



## DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

### Doctorate in Clinical Psychology: Main Research Portfolio

**1) Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies; 2) A Different Connection: Young People's Views of Treatment Sessions delivered by Skype in a Specialist Paediatric Chronic Fatigue Service; 3) Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems.**

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# **Research Portfolio Submitted in Part Fulfilment of the Requirements for the Degree of Doctorate in Clinical Psychology**

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Doctorate in Clinical Psychology

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May 2017

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## **Word Counts**

Critical Review of Literature: Sexuality in the Lives of People with Learning Disabilities:  
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## Table of Contents

List of abbreviations .....	1
List of figures .....	2
List of tables .....	3
Abstracts .....	4
<b>Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies</b> .....	7
Introduction .....	8
Method.....	10
Synthesis.....	12
Discussion.....	18
Implications for practise .....	21
Conclusion.....	22
References .....	23
<b>A Different Connection: Young People’s Views of Treatment Sessions delivered by Skype in a Specialist Paediatric Chronic Fatigue Service</b> .....	25
Introduction .....	26
Method.....	27
Results .....	29
Discussion.....	33
Recommendations to the CFS/ME Service and potential improvements .....	34
Conclusion.....	34
References .....	36
<b>Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems</b> .....	38
Introduction .....	39
Method.....	42
Results .....	47
Discussion.....	53
Conclusion.....	58
References .....	59
Executive summary of main research project .....	62
Connecting Narrative.....	64
Acknowledgements .....	70
Appendices .....	71

## **List of abbreviations**

CADS	The Cognitive Appraisal of Disclosure as a Stressor
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CFS	Chronic Fatigue Syndrome
CMM	Coordinated Management of Meaning
CYP	Children and young people
GET	Graded Exercise Therapy
HOP	Honest, Open Proud programme
ME	Myalgic Encephalomyelitis
MSPSS	Multidimensional Scale of Perceived Social Support
NICE	National Institute for Health and Care Excellence
PWLD	People with learning disabilities
SSMIS-SF	The Self-Stigma of Mental Illness Scale-Short Form
SIP	Service Improvement Project
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale

## List of tables

### **Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies**

Table. 1. <i>Search Terms</i> .....	Page 11
-------------------------------------	---------

### **Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems**

Table 1. <i>Demographic characteristics of participants (N=831)</i> .....	Page 43
Table 2. <i>Questionnaires completed by participants</i> .....	Page 44
Table 3. <i>Summary of stepwise linear multiple regression analysis for variables associated with disclosure-stress (CADS scores; N = 772)</i> .....	Page 49

## **List of figures**

### **Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies**

*Figure 1.* PWLD sexuality within the CMM hierarchical model.....Page 18

### **Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems**

*Figure 1.* Correlation of the CADS at time 1 and time 2.....Page 48

### **Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic Synthesis of Qualitative Studies**

**Background.** The normalisation movement calls for more recognition of the sexual rights of people with learning disabilities to challenge classically paradoxical cultural beliefs: ‘hypersexual’ versus ‘asexual’.

**Aims.** This meta-ethnographic qualitative synthesis aimed to explore the voices of people with learning disabilities in regards to their experiences and perceptions of sexuality using a Coordinated Management of Meaning framework to derive new conceptual understandings of how their sexuality exists within multiple contexts.

**Methods and Procedures.** A systematic literature search and quality assessment yielded 16 studies that met the inclusion criteria and were synthesized following the method of meta-ethnography.

**Outcomes and Results.** Four core themes were identified; ‘Sociocultural Norms’; ‘Under Others Power’; ‘Sexual Identity’ and ‘Sexual Experience’.

**Conclusions and Implications.** Application of the hierarchical Coordinated Management of Meaning model suggested carers contextual beliefs about people with learning disabilities’ sexuality inhibited or facilitated positive expressions of sexuality over and above individual needs and desires. Rights-based cultural messages provided the only context that led to positive sexuality outcomes and research that explores sexuality within this context is much needed. The Coordinated Management of Meaning model identified by this research may act as a framework to support the reflective-practice of carers.



## **A Different Connection: Young People's Views of Treatment Sessions delivered by Skype in a Specialist Paediatric Chronic Fatigue Service**

**Background.** There is a lack of local specialist services for children and young people with CFS/ME in the UK. The vast distances some families have to travel to reach specialist services can be a barrier to accessing evidence-based treatment, particularly for children and young people who are fatigued and for whom travelling can be very difficult. Specialist services are therefore harnessing videoconferencing technology such as Skype to deliver sessions remotely.

**Method.** Qualitative interviews explored the views and experience of 8 young people (age 9 - 16) of follow-up sessions delivered by Skype within a specialist CFS/ME service. Interviews were analysed thematically.

**Results.** Three main themes were identified; 'A different connection': Therapeutic experience and engagement; 'It was a little chaotic, but it was ok': Anticipations, preparations and technology use; and 'It was way easier to access': Accessibility and the impact of CFS/ME symptoms.

**Conclusions.** Young people reported they were able to overcome potential barriers (e.g. technology issues, worries and anticipations) to therapeutically engage with treatment through the use of Skype. Although the young people valued face-to-face appointments, the convenience of attending Skype sessions from their own homes reduced the burden of travel, reduced school absence and facilitated a greater sense of control of their environment. A list of recommendations about using Skype was presented to the team and an information leaflet was developed to improve the service the CFS/ME team were able to offer young people and their families.

## **Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems**

Individuals who experience mental health problems continually make disclosure decisions based upon assessments of the potential benefits, costs and risks associated with the disclosure. Due to the potential stress some people may feel around disclosure, our research aimed to adapt an existing questionnaire in order to measure disclosure-stress (the cognitive appraisal of disclosure as a stressor measure) and to identify associated-factors. We used a mixed-method design to collect quantitative data (n=831) and qualitative data (n=12) to produce a rich account of factors associated with disclosure-stress. Results indicate the cognitive appraisal of disclosure as a stressor measure to be a reliable measure of disclosure-stress. Lower levels of psychological wellbeing, lower numbers of disclosure, less satisfaction with number of disclosures, being female, and less social support were all found to be associated with higher disclosure-stress. Additional analysis identified that individuals who had experienced a more publically stigmatised mental health problem (personality disorder, bipolar disorder, schizophrenia or psychosis) experienced significantly more self-stigma, disclosure-stress and lower social-support but also higher numbers of disclosure than the rest of the sample. Qualitative analysis highlighted potential benefits, costs and risks that individuals consider when making disclosure decisions. Potential factors that increased disclosure-stress included recent diagnosis, disclosure during an acute episode of the mental health problem and being male. Triangulation of the quantitative and qualitative results allowed for rich interpretations of the findings and conclusions to be drawn about which factors are associated with disclosure-stress. Suggestions for future research and clinical implications are discussed.

**Sexuality in the Lives of People with Learning Disabilities: A Meta-Ethnographic  
Synthesis of Qualitative Studies**

Candidate: Charlotte Whittle

Supervisor: Catherine Butler

Word count: 5,722

Target Journal: Research in Developmental Disabilities (Appendix A)

*This journal was selected because of its high impact factor in learning disabilities  
research.*

## Introduction

Sexuality is ever-present in our everyday lives and is a fundamental human right for all ages, genders, sexual orientations and levels of cognitive development (Ailey, Marks, Crisp, & Hahn, 2003). It is a complex area of human experience involving emotions, biology, beliefs, morals and social behaviours strongly influenced by culture and context. A person's sexuality can considerably influence the formation of their identity, self-esteem and relationships (Ailey et al., 2003; Sheehy, 2000).

Adding to the complexity of sexuality itself is the intersection of other axis of power and socially constructed meanings such as gender and learning disabilities. This review will examine how those with learning disabilities experience their sexuality. Latest statistics, estimate that there are just under 1 million people with a learning disability (PWLD) living in the UK (Public Health England, 2016). Living with family or friends is now the most common living arrangement for PWLD with long-term social care support. However, living in registered care homes and supported accommodation are still also very common experiences for PWLD (Public Health England, 2016).

Whether living at home or in supported accommodation, the norms and lived experiences of PWLD are shaped by social norms, often reflected in national and local policy. The normalisation movement led to national deinstitutionalisation for PWLD in the 1970s. This change implied a shift in philosophy and ideology which emphasised the rights of PWLD to live a 'normal' life and make their own choices (Barr, McConkey, & McConaghie, 2003; McCarthy, 1999; Parley, 2001). Before the 1970s, PWLD's sexuality was actively repressed and denied by the segregation of sexes, however this movement recognised the right of PWLD to determine their own sexuality. However, as services moved towards a model of normalisation, services stopped explicitly denying PWLD sexuality, but developed a role in managing the sexuality of PWLD based on the social-cultural norms of the non-disabled (McCarthy, 1999). Brown (1994) suggested that normalisation is restrictive when applied to sexuality of PWLDs as what is considered 'normal' is determined by socialisation and variations in sexual expression are not freely accepted.

A lack of direction, support, consideration and confidence in how the normalisation principle translates into clinical practice has led to PWLD being discouraged to develop or express their sexuality through the service implementation of rules and restrictions, lack of education and lack of support (Johnson, Frawley, Hillier, & Harrison, 2002; Löfgren-Mårtenson, 2004; Pownall, Jahoda, & Hastings, 2012; Taylor-Gomez, 2012).

## **The Paradoxical views of PWLD sexuality**

A well-documented paradox exists regarding how services and carers often view the sexuality of PWLD (Dotson, Stinson, & Christian, 2003). On one hand, PWLD are viewed as needing protection from sex as they are viewed as 'asexual' (McCarthy, 1999; Yau, Ng, Lau, Chan, & Chan, 2009) without capacity for sexual desire (Bunyan et al., 1986; McCarthy, 1999; Taylor-Gomez, 2012), but on the other hand, PWLD are viewed as 'hypersexual', and that society needs protecting against PWLD's sexuality (Lesseliers & Van Hove, 2002; Taylor-Gomez, 2012).

These stereotypes may act to sabotage development of a realistic representation of the sexuality of PWLD. Of course, there is now a third view: that PWLD are sexual beings and are capable of, and show, a desire to have positive sexual lives (Deeley, 2002). However, as professionals and carers can hold one or all of these views, they may experience conflict on how best to support PWLD, and commonly resort to strategies of over-protection (Deeley, 2002; Hollomotz, 2011). As cultural values impact greatly on the development of sexuality, the more that PWLD are 'protected' from sexuality, the more inexperienced, uneducated, vulnerable and dependent they may become. Therefore, overprotection becomes a self-fulfilling prophecy, disabling PWLD from becoming socially and sexually competent.

However, there has been an increase in the positive promotion of PWLD sexuality (DOH, 2001, 2009; Executive, 2000; McCarthy & Thompson, 1995). A growing number of self-advocacy groups and an increase in qualitative research which aims to give PWLD a voice to express their views about sexuality and intimate relationships to replace the dominant assumptions of the non-disabled and influence practice, policy and ultimately their own relationships. PWLD are aware of their rights to have relationships and want choices about the types of relationships they have and what support they need to have them (Kelly, Crowley, & Hamilton, 2009). Understanding how sexuality functions in the lives of PWLD is critical to implementing assistive and supportive services.

## **The Coordinated Management of Meaning**

One model that may be helpful in unpacking how sexuality and learning disabilities intersect at the level of society and the individual is the Coordinated Management of Meaning (CMM) (Pearce & Cronen, 1980). CMM proposes that communication is performative in such a way that people co-construct their social realities through the process of communication within a multitude of contexts. CMM is interested in the form of the communication rather than its content and describes communication acts as 'doing things'. Therefore, CMM describes communication as not just occurring through

language, but as ‘acts’, for example someone choosing to express their sexuality and how they do this would be in itself a communication. Communication is also reflexive, in that communicative acts and the social worlds that we create also affect and shape us. The hierarchical model of CMM proposes that meaning is dependent on the context in which it occurs, but that communication acts always occur in multiple contexts. No matter what the speaker says, the words of the story will only make sense if they are understood within multiple contexts: culture, relationships, personal identity and momentary episodes. The layers of context are an essential component of CMM theory as the higher contextual levels have a greater influential force than the lower ones (the contextual force). Therefore, if culture is the highest context, the cultural messages about the sexuality of PWLD will have more influence over the relationships, identities and episodes of sexuality.

Whilst CMM began as an interpretive communication theory, it has now established itself as a practical theory aiming to join people in various systems and situations to articulate the knowledge needed to act constructively. CMM aims to construct better social worlds by using the hierarchical model to elaborate multiple meanings and stories, evaluate how stories can be interconnected, recognise which context is privileged and why and make suggestions to intervene at different points.

This meta-ethnographic qualitative synthesis will focus on the voices of PWLD by examining the qualitative literature. Although most of the sexuality and PWLD research focuses on the voices of carers, a substantial qualitative literature now exists on the sexuality of PWLD. This synthesis of the literature aims to explore the experience and perceptions of PWLD on sexuality and will use a CMM framework to derive a new conceptual understanding of the existing literature and make recommendations to improve practices.

## **Method**

### **Systematic literature search**

In order to identify relevant studies to be included in the review a systematic search of the published literature was conducted in July 2016. A combination of search terms was generated (Table. 1). The initial search yielded a large number of papers that were filtered down (Appendix B) to a final list of articles to be included in this review (Appendix C).

Table. 1. *Search Terms*

	Search Terms	Search Criteria
AND	Learning Disability* OR LD OR Intellectual Disability*	All dates
	Intimate* OR close* OR sexual* OR Sex OR Love* OR sexuality*	Article titles
	Experience* OR Qualitative	

### **Inclusion criteria**

Studies that met the following inclusion criteria were included in the review:

- Studies that employed a qualitative methodology (e.g. interviews, focus groups etc) or mixed method (provided the qualitative results were reported separately).
- Published in peer-reviewed journals.
- Written in English.
- Studies which had adults with learning disabilities as the primary informant; if articles included participants under the age of 18 and the data had not been separately analysed, articles were excluded.
- Studies that specifically focused on sexuality or intimate, romantic or sexual relationships.
- Studies not primarily focused on instances of sexual abuse or rape.
- Studies focused on a community sample (not including people in secure services).

A random selection of eight articles which were selected to be included in the synthesis and a random selection of eight articles which were excluded from the synthesis were reviewed by an independent researcher against the inclusion criteria. The independent researcher and the lead researcher had 100% agreement of the selected articles included and excluded from this review.

### **Selecting the studies**

In order to select the final studies, identified potential studies were read and re-read and examined in terms of quality using the critical appraisal skills programme qualitative checklist (CASP qualitative checklist) (Critical Appraisal Skills Programme, 2017) to

appraise each paper (Appendix D). The CASP qualitative checklist is a specially designed tool to enable researchers to evaluate qualitative research papers. Each paper was scored on a scale of 0-2 depending on the amount of information the paper provided in each category (as described by Duggleby et al. (2010) and Rushbrooke, Murray, and Townsend (2014)). Articles that scored ten or less were excluded from the review. Four papers were randomly selected and scored by an independent researcher. An interrater reliability analysis using the Kappa statistic was performed to determine consistency among raters; Kappa = 0.54 ( $p < 0.001$ ) indicating moderate agreement between the two researchers (Landis & Koch, 1977). Two articles were excluded based upon a CASP score of lower than 10.

### **Analysis and synthesis of the selected studies**

The method used to guide the synthesis followed that of meta-ethnography developed by Noblit and Hare (1988) and based on the particular method described by Malpass et al. (2009), for example the themes identified by the paper authors (the second order constructs) become the data rather than the quotes themselves (the first order constructs).

The selected studies were carefully read and re-read in order to identify the main concepts and details were recorded (e.g. setting, participants etc) to provide the context for interpretations made of each study. The next step involved determining how the studies were related to each other. This involved looking across the different papers for common and recurring concepts. In this way, the studies to be synthesised were treated in a similar way to primary data. Next, to translate the second order constructs across the 16 papers, each was entered into a spreadsheet with the corresponding paper number in the final column and a summary definition was provided for each one, often using the original terminology provided in the papers where appropriate. We were then able to read and re-read all of the second order summaries in order to determine overlap and write a translation of each second order construct across all 16 papers. The final stage involved synthesizing the translations by creating third order constructs that represent the views and interpretations of the synthesis. This stage was completed by the research team through discussion and feedback and finally expressed in terms of themes and key concepts (Appendix E).

### **Synthesis**

Four core themes were identified across the studies; 'Sociocultural Norms' within the context of cultural beliefs of PWLD, 'Under Others Power' within the context of



relationships, 'Sexual Identity' within the context of identify, and 'Sexual Experience' within the context of episode. A number of subthemes were identified and are described within each layer of context.

### **Cultural Beliefs of PWLD: Sociocultural Norms**

PWLD appeared to ascribe to very traditional sociocultural norms in terms of sexuality and intimate relationships. The majority of papers reported that PWLD had a desire to be involved in an intimate relationship. PWLD in these studies expressed dissatisfaction with being single and felt they needed to have a partner to be fulfilled. However, some did report that having a relationship was not important for them and tended to reference external, social constructions of relationship difficulties as deterrents: e.g. they would have to buy gifts for their partner and it would be expensive.

Some PWLD perceived it was easier for non-disabled people to maintain and establish relationships. Many expressed a desire to have a partner of average intelligence, but all who had partners, had partners with a learning disability. They believed that perceptions of beauty and stereotypes of learning disabilities acted as a barrier to forming relationships with others. PWLD reported feeling they were treated unfairly in how decisions about their relationships are made.

Many PWLD believed being in a relationship made them happier, more confident and increased their independence. Intimate relationships were seen by PWLD as a source of support and important to provide a sense of security, shared mutual connection, reciprocity and companionship. PWLD in these studies described being committed and devoted to their relationship and enjoyed talking to each other, spending time together, taking care of each other and buying each other gifts.

However, PWLD gave no consideration of anything other than a heterosexual relationship within the studies. Many could not identify or name different sexual orientations and for the majority of those that could, they described these as 'wrong' and 'horrible'. Additionally, three quarters of the studies reported on PWLD's traditional views about marriage. PWLD in these studies held a conventional and stereotyped view that sex only occurs within a monogamous marriage and only for the purpose of procreation. This message appeared to be passed down through the views of professional staff and families. If unmarried, PWLD believed that as a very minimum sex should be with someone you really love, rising to feelings of shame at engaging in pre-marital sex.

Most PWLD in these studies expressed a strong desire for future commitment, marriage and the possibility of having children. For many, marriage signified freedom, independence, happiness and a better future. For some, they had no desire to marry

because of the belief it would be too difficult; paperwork associated with marriage, helping children with homework, too expensive and might end in quarrels and fights.

Three studies highlighted the gender stereotypical ideas PWLD hold about men and women in relationships, according to gender roles expected within social norms. These beliefs seem to be reinforced by the environments that PWLD often found themselves in, for example day centres, whereby women took part in activities such as knitting and sewing and men engaged in activities such as woodwork. Additionally, support staff were usually women and managers or positions of power were usually occupied by men.

### **Relationships: Under Others Power**

PWLD experienced excessive rules and restrictions imposed by support staff and carers in relation to sexual behaviours and intimate relationships. In some cases, PWLD experienced being chastised by staff for engaging in ‘restricted’ behaviours. PWLD felt as though agencies prohibited expressions of sexuality ranging from displays of affection to sexual intercourse.

Some PWLD reported experiencing pressure to end relationships and feared the consequences of engaging in ‘prohibited’ behaviours. Fear of losing a valued person or relationship due to one person being moved to another supported home was identified in five studies. Established relationships did not appear to be considered when organising social housing and many felt forced to end relationships due to moving. Sometimes this move was experienced by PWLD as a punishment for engaging in ‘prohibited’ behaviours and the fear of involuntary separation was reported as influencing decisions to commit to future relationships.

Feelings of being monitored and not trusted were reported by PWLD who often felt as though they were not offered appropriate levels of privacy. Despite wishing to engage in intimate or sexual relationships, they felt they were never provided with the opportunity to be alone with their partner.

Language and descriptions reported in the research were akin to adolescent relationships. PWLD reported being perceived by others as ‘grown up children’ and treated in the same manner; carer impulses to keep them safe denied them the rights to experience full life and learn from their mistakes.

A number of studies reported on the external management of PWLD’s sexuality and relationships. In these studies, PWLD viewed caregivers as the greatest support or barrier to their sexuality. Some felt they could discuss relationships with their family members but others felt as though family and staff held the power to provide or withhold

sexual information, living arrangements etc and these decisions were sometimes made against their will. Most experienced constant warnings and restrictions by family and staff to abstain and protect themselves and others from their sexuality. Depending on the nature of the external power, PWLD reported expressing powerless positions whereby they felt unable to assert their sexuality and felt forced to follow the dominant opinions of others.

Over half of the studies reported that PWLD held incomplete or inaccurate knowledge of relationships, sex, bodily organs and function. Information provided by staff or families tended to focus on protective measures, basic function and negative consequences. Some PWLD described their lack of knowledge as a barrier to engaging in sexual behaviours. Perhaps due to a lack of information, many PWLD described acquiring their knowledge of sex and sexual behaviours through random and opportunistic ways: for example, watching others on television, reading about it in magazines or by watching pornography. This appeared to lead to partial, inconsistent and skewed views of sex and relationships. For some, this skewed view of sex left them believing sex would be too aggressive and therefore anxiously avoided it.

PWLD received numerous messages of sex as 'dangerous' and some were solely communicated the negative consequences of sex. Within the studies, many PWLD described sex as 'dirty' and 'disgusting' and were afraid of consequences such as pregnancy and STDS. Some could only associate sex with sickness and disease.

PWLD desired to be supported to maintain and establish relationships, express their sexual needs and help manage and resolve relationship conflicts. PWLD valued talking to someone about their relationships (e.g. care staff, parent, friend). However, they also reported very different experiences in actually receiving this support, ranging from caregivers outright refusing to provide this support, leaving PWLD with no opportunity to talk about their relational and sexual feelings, to feeling well supported in their relationships.

PWLD lives appeared to revolve around reliance on assistance to provide practical support to assist adaptive behaviours, for example they needed transportation to maintain and facilitate personal relationships. In these cases, caregivers acted as gatekeepers to socialisation and PWLD felt they had infrequent opportunities to meet with others and felt unable to socialise outside of their pre-arranged social groups. Due to this, PWLD could experience loneliness and a lack of intimacy in their lives. They reported that professionals could think it adequate to provide activities for PWLD to combat loneliness but this failed to fulfil their need for intimacy.

## **Identity: Sexual Identity**

Some PWLD did not identify as having a learning disability, but understood this was a label given to them by others. Instead, they identified themselves as being as 'normal' as everyone else and strived to live their life this way. Those who did accept the learning disability label struggled to understand and talk about what it meant.

Four studies described how PWLD were able to hold a positive sexual identity and were aware of their erotic potential to be sexual. They noticed themselves as sexually desirable to others and had a desire to engage in sexual activities with a partner or future partner. One study reported that most of the participants had engaged in sexual intercourse during their lives, but actual experiences of engaging in sexual intercourse and sexual behaviours were largely missing from the research. An erotic self-identity was also present in more subtle contexts such as having hope for the future, holding a desire to be seen by others as adults with rights, choices and aspirations to be accepted as sexual beings. Whereas more overt expressions were much more rarely described in the studies.

A more persistent theme described by seven studies identified PWLD's tendency to distance themselves from their sexuality. PWLD in these studies portrayed ambivalence and denial towards their own sexuality. The studies described how PWLD anxiously defended against their sexuality by hiding or suppressing the possibility of any form of sexual relationship, as though they did not in fact identify as sexual beings. The studies described how many PWLD find discussing sexuality embarrassing and try to distance themselves from talking about sex, making indirect references to physical relationships.

A number of studies referred to the internal battle PWLD experienced when considering or expressing their sexuality. This conflict arose between the sexual norms prescribed to PWLD by the external world (e.g. staff, families and society) that they should not act on their individual needs and desires and their internal sexual feelings and desires. PWLD felt as though their own wishes could be engulfed by opposing influences and this often led to feelings of shame.

## **Episode: Sexual Experience**

Many PWLD expressed their sexuality through intimate behaviours such as kissing, cuddling, hugging and hand holding but did not engage in more explicitly sexual behaviours including sexual intercourse. It seemed as though many participants did not want more from their relationships than these behaviours. These behaviours were also felt by participants to be important in order to build a relationship and indicated emotional closeness, intimacy and enjoyment within a relationship.

Two studies that reported on PWLD's experience of sexual behaviours identified communication between partners as key. PWLD felt that talking about their sex life created a basis whereby they could carefully explore and respect each others boundaries. The women in the studies wanted to be treated gently and tenderly in personal interactions and the men also described wanting a peaceful approach. Being open with communication allowed the men to be tolerant and accepting of the women who did not want to engage in intercourse. The experience of being patient and gentle before and during intimate experiences, seemed to allow partners to be more open to new experiences.

Mixed views were presented on engaging in masturbation. Some studies described participants as not knowing what masturbation was or what it involved where as others described participants as actively engaging in masturbation, describing it as an important aspect of their lives as the only outlet to fulfil their sexual desires and release tension. However, it was far more common for studies to talk about negative sexual experiences rather than positive, with seven studies detailing negative experiences of sexual contact. Within these studies, some PWLD had past experiences of sexual abuse and exploitation. These experiences seemed to strongly influence their negative views of intimate relationships and their decisions on how they engaged in future relationships or not, as the case may be. Not being able to talk to others (e.g. support staff) about how they were feeling or their experiences, made PWLD more vulnerable to abuse.

Four of the studies reported that language used by PWLD to describe sex rarely contained words that described pleasure. Many women in these studies rarely appeared to experience sexual desire and consented to passive pleasure-less sexual acts in the belief it was their role as a woman. If pleasure was described, this was usually an extension of the overall mutuality of the relationship and both men and women could find sexual relationships satisfying but not stimulating; very few could describe an orgasm.

PWLD appeared to engage in several protective sexual strategies to avoid either unwanted sexual consequences or reactions from others. For some, they engaged in self-imposed abstinence to protect against negative consequences such as AIDS, pregnancy and negative reactions from staff and families. For some PWLD who had experienced abuse, they reported avoiding all 'risky' situations to protect themselves against the occurrence of potential future abuse. Additionally, in response to restrictive and prohibitive climates and to prevent upset and negative reactions from others, some PWLD felt they could only assert their independence by resorting to secrecy to satisfy their sexual needs and engage in intimate activities by opportunistic and surreptitious means.

## Discussion

This meta-ethnographic synthesis brings together the voices of PWLDs and provides the literature with a view of the complexity of the issues involved in the topic of PWLD's sexuality.

Using a CMM framework (Figure. 1), we have identified how PWLD's sexuality exists within the contexts of the cultural beliefs of carers (as described in the existing literature: hypersexual, asexual and rights-based), cultural beliefs of PWLD (sociocultural norms), relationships (under others power), identity (sexual identity), and episode (sexual experience). By adapting the CMM hierarchical model to account for the three cultural beliefs held by others, we are able to notice repetitive patterns between PWLD and their carers, professionals and families that inhibit or facilitate PWLD's right to sexuality.

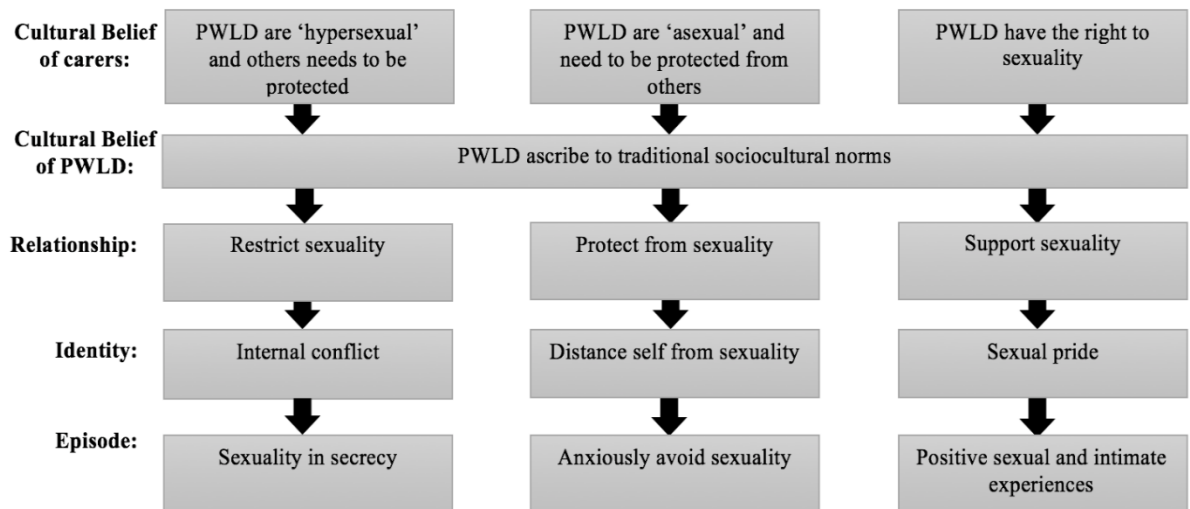


Figure 1. PWLD sexuality within the CMM hierarchical model

It appears as though carers can be working within all three contexts at one time, and can move between contexts at different times. What appears to be most significant is how these contextual forces influence the communication acts in the subsequent contexts and this process will be described and discussed.

Moving through the model, we can see how PWLD ascribe to very traditional sociocultural norms in terms of sexuality. They hold traditional views on gender roles and marriage and associate happiness with aspiring to be in a traditionally defined heterosexual relationship. These cultural beliefs seem to exist based on information provided to them by their external environment (e.g. carers, professionals, families, the media etc).

If the cultural message is that PWLD are 'hypersexual' and others should be protected from their sexuality, then even if PWLD desire to express their sexuality in line

with their traditional sociocultural norms, the relationship context between the PWLD and carers will be more influenced by the higher level of culture. Resulting in carers 'restricting' PWLD from expressing their sexuality rather than focusing on the individual's needs and desires. This seems to co-construct a meaning of internal conflict at the identity level as PWLD report feeling desire but also feeling it is not acceptable within the wider context. In the context of the episode, this then means PWLD act to communicate their sexuality by expressing it in secrecy, thus putting them at risk and at a greater vulnerability to negative sexual and intimate encounters.

If the cultural message is that PWLD are 'asexual' and need to be protected from their own sexuality, then again their desire to express their sexuality will not have the strongest contextual force. The relationship level will be more influenced by the higher cultural context so that carers act to protect PWLD by not exposing them to their potential sexuality. These contexts co-construct a meaning of distancing the self from sexuality in PWLD as they describe sexuality as something 'funny' or 'embarrassing' or unfortunately but more commonly, 'dangerous' or 'disgusting'. Within the context of episode, PWLD then communicate their sexuality by trying to protect themselves from it; they act to anxiously avoid sexual or intimate encounters or practice abstinence. This pattern of communication also appears to leave PWLD at risk and vulnerable to negative sexual and intimate encounters.

If the cultural message is that PWLD have the right to express their sexuality and the PWLD's culture is that they wish to pursue their sexuality within their cultural norms, then the relationship of the carers to the PWLD communicates emotionally and practically supportive acts. These contexts filter down to construct a meaning of 'sexual pride' for PWLD as they endorse their sexuality and become more aware of their sexual potential. In the context of the episode, PWLD can communicate their sexuality by exploring and engaging in positive, pleasurable sexual experiences and intimate relationships characterised by open and respectful communication between partners.

By examining the model we can see that the only opportunity that leads to positive outcomes for the sexuality of PWLD are when right-based cultural messages produce a dominant cultural force that influences the other layers of context to support sexuality, encourage and foster sexual pride and embolden PWLD to positively explore their sexuality.

However, this meta-ethnographic review has shown that out of the three hierarchies, evidence for the rights-based model is least reflected in the data. PWLD described their carers as the biggest support or barrier to expressing their sexuality and the studies reported far more instances of barriers to sexuality than support. Sexual pride was

only reported by four papers, and only one that did not report this as an exception to the majority of negative sexual identity stories. Perhaps most striking is the distinct lack of studies that report on positive sexual experiences and intimate relationships in the lives of PWLD. This may be a methodological issue (i.e. perhaps contextual forces have been so strong that research has commonly focused on the negatives rather than the positives) but due to the number and breadth of studies that have now been conducted in this area and have been reviewed by this synthesis, it now seems more likely that the ‘hypersexual’ and ‘asexual’ contextual forces are influencing the layers of context in such a way so that the majority of PWLD are unable to have positive sexual and intimate experiences within the episode context.

A meta-synthesis examining carer’s attitudes towards PWLD’s sexuality highlighted many carers held cultural beliefs within a right-based context, and although carers experienced hypersexual and asexual cultures in the research, the authors describe these themes as present but not pervasive (Rushbrooke et al., 2014). But despite this, the current meta-ethnographic synthesis examining PWLD’s views and experiences has found a real lack of evidence documenting the rights-based context of supporting PWLD to explore their sexuality. It appears as though there are distinct differences between the stories told by carers and stories lived; although the majority of carers may hold rights-based cultural beliefs about PWLD’s sexuality, these beliefs may not hold the greatest contextual force when hypersexual and asexual contexts are present and may not translate into positive communicative acts that respond to the individual need and desire of PWLD. As Rushbrooke et al. (2014) describe, carers of PWLDs can feel like they must play the role of ‘protector and risk manager’ and perhaps this references a higher contextual force that may be beyond the scope of this study: the political and legal framework that influences the culture of carers. This highlights the need for carers to feel more confident using the legal framework to make decisions based on their rights-based cultural beliefs that will increase autonomy and independence in PWLD when exploring their sexuality.

While this meta-ethnographic synthesis has used a CMM framework to focus specifically on sexuality within the lives of PWLD, this framework could be used to examine the cultural impacts of multiple forms of sexuality. For example, the experience of other minority groups, such as people with physical disabilities, are often influenced by cultural beliefs of ‘asexuality’ which influence their encounters with professionals to limit the exploration of sexual pleasure (Tepper, 2000). In fact, when examining the wider sexuality literature, it becomes clear that cultural beliefs not only influence the sexual experience of PWLD, but other minority groups and their positive and negative impact needs to be explored further. However, despite similarities with other groups, there



appears to be an important and significant difference when examining the sexuality of PWLD; the number of contrasting cultural beliefs that can lead to significantly different expressions of sexuality.

### **Limitations**

This meta-ethnographic synthesis utilised the CASP in order to only include research of a medium to high quality. However, there is a potential risk with this approach that valuable insights into the topic may be excluded from synthesis. Research rated as “low quality”, for example due to methodological flaws, may nonetheless generate new insights and rich data, whereas methodologically sound research might lack richness and lead to poor insight into the phenomenon (Dixon-Woods et al., 2007). On further reflection, the studies excluded from this research did not appear to offer original insights not already included in the review. Additionally, findings did not appear to vary according to the quality of the studies and therefore richness of the data was determined not to have been lost due to the use of CASP.

### **Implications for practice**

We hope this meta-ethnographic synthesis will stimulate discussion within carers when working with sexuality and PWLD by acknowledging it is essential to recognise the layers of context in which they and the people they work with are performing communicative acts. This can only be done by increasing awareness of existing patterns and encouraging reflective-practice that leads to behavioural change. We encourage carers and professionals to use the model outlined by this meta-ethnographic synthesis as a guide to inform self-reflection about how they and their clients are co-constructing sexuality meanings. We encourage carers to consider the following questions outlined by Schnitman (2004) to support their self-reflective practice:

- In what context is this situation located?
- What would this situation meaning be like in another context?
- What conditions favour this situation meaning/s?
- What context offers better conditions for this situation?
- Is it possible to move this situation into other more favourable contexts?
- Additionally, carers should consider what actions they can take that will lead to positive behavioural changes based on their reflections, therefore moving towards practical applications of the theory to change social worlds.

This meta-ethnographic synthesis also highlights a real need for future research to focus on PWLD who experience their sexuality within a rights-based context: how does this influence their relationships with carers? their identity? episodes of sexuality expression? and what can we learn from these contexts that will improve the lives of PWLD?

### **Conclusion**

PWLD have the right to express and explore their sexuality. However, this meta-ethnographic synthesis that explored their views in regards to their sexuality has highlighted overwhelmingly negative experiences and perceptions held by PWLD. As existing literature describes, carers of PWLD can draw upon 'hypersexual', 'asexual' and 'rights-based' contexts. This meta-ethnographic synthesis has found evidence for the application of the hierarchical CMM model that appears to suggest carers overarching contextual beliefs about PWLD's sexuality influences subsequent layers of context that act to either inhibit or facilitate positive expressions of sexuality. It appears rights-based cultural messages provide the only context that leads to positive outcomes for the sexuality of PWLD. By influencing subsequent layers of context to support sexuality, rights-based cultural messages encourage and foster sexual pride and embolden PWLD to positively explore their sexuality. However, qualitative research that explores PWLD's sexuality within a rights-based context is significantly lacking and is a much needed area for future research. We hope that services will use the CMM model identified by this research as a framework to support the reflective-practice of carers in the future. Carers should also be supported to work within a rights-based context that allows them to feel more confident applying the legal framework to respond to individual needs and desires and therefore improve the social worlds of PWLD.

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**A Different Connection: Young People's Views of Treatment Sessions delivered by  
Skype in a Specialist Paediatric Chronic Fatigue Service**

Candidate: Charlotte Whittle

Internal Supervisor: Maria Loades

External Supervisor: Jennifer Collins

Word Count: 3,537

Target Journal: Clinical Child Psychology and Psychiatry (Appendix F)

*This journal was selected due to multiple publications of qualitative research regarding paediatric chronic fatigue syndrome. Additionally, it publishes manuscripts with word counts over 3,000 words.*

## **Introduction**

### **Chronic Fatigue Syndrome (CFS/ME)**

CFS, also known as myalgic encephalomyelitis (ME), is characterised by debilitating and unexplained severe mental and physical fatigue that is not alleviated by rest (NICE, 2007; Prins et al., 2001). Prevalence of CFS/ME in children and young people (CYP) is estimated to be between 1% and 2.4% (Crawley, 2013; Garralda & Chalder, 2005; Mackenzie & Wray, 2013). This group often find it difficult to attend school and maintain social contact (Crawley, Emond, & Sterne, 2011), feel isolated, lack independence (Winger, Ekstedt, Wyller, & Helseth, 2014) and are at increased risk of suffering from comorbid mental health difficulties (Fisher & Crawley, 2012; Matsuda et al., 2009).

### **Specialist Paediatric Service Provision for CFS/ME**

NICE (2007) guidance recommends that CYP with mild/moderate CFS/ME should access Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) or Activity Management from a specialist service.

The ME Association (2010) reported that CYP rated a specialist CFS/ME centre as their first choice for receiving treatment. However, in the UK, only approximately 10% of CYP have access to a local CFS/ME specialist service (Crawley, 2013). One alternative is to receive treatment remotely through videoconferencing.

### **Videoconferencing and the use of Skype**

Little is known about whether Videoconferencing (e.g. Skype) is an effective method of delivering intervention in paediatric psychological treatment. However, little difference in outcome was reported during an 8-week CBT programme for childhood depression that compared face-to-face and videoconferencing delivery methods (Nelson, Barnard, & Cain, 2003).

CYP report a number of potential benefits of videoconferencing; rating it as good as in-person consultation, preferable to travelling vast distances, less financially burdensome and less disruptive to schooling and home routines (Grealish, Hunter, Glaze, & Potter, 2005; Wood et al., 2016). Potential disadvantages of videoconferencing include a lack of personal interaction, difficulty discussing sensitive problems and issues with technology (Goss, Goss, & Goss, 2015; Simeonsdotter Svensson, Pramling Samuelsson, Hellström, & Jenholt Nolbris, 2014).

No published study has explored the use of videoconferencing in paediatric CFS/ME, but limited research in adults has reported that patients felt able to build rapport

when attending review sessions by videoconference (Weatherburn, Lister, & Findley, 2007).

The most recent review concluded that videoconferencing may be a pragmatic and beneficial means of service delivery, but there is currently not enough formal evidence in favour of, or against its use in patient care (Armfield, Bradford, & Bradford, 2015).

Therefore, it is important to understand the potential role, risks and benefits of videoconferencing in clinical practice. This study aimed to explore CYP's views of treatment delivered by Skype in a specialist paediatric CFS/ME team which has been offering follow-up sessions by Skype as a pragmatic solution to geographical barriers CYP face in accessing the service. The research questions were; what are CYP's perceptions and experiences of using Skype to attend treatment? and what improvements could be made to the service the CFS/ME team provide to support CYP's experiences of sessions provided by Skype?

## **Method**

### **Setting**

The study was based in a Specialist Paediatric CFS/ME service in the UK. The service provides multidisciplinary assessment and evidence-based treatment for CYP up to the age of 19.

The service introduced the option of Skype sessions as an alternative means of delivering evidence-based therapies due to the vast geographical area it covers.

### **Design**

The study used a qualitative design due to its flexibility when exploring participants' experiences and perceptions.

### **Participants**

CYP were eligible to participate if they were 18 or under, receiving treatment within the specialist CFS/ME team, and were well enough to complete an interview. Participants were recruited through their healthcare professional in the CFS/ME team and were identified if they were actively attending treatment through Skype, had attended treatment through Skype previously, or had declined to use Skype. Participants were recruited until data saturation was reached; a total of 8 participants (Demographic information presented in Appendix G) were recruited between the ages of 9 and 16 (6 female and 2 male; five were actively attending sessions by Skype, one previously attended by Skype and two declined Skype sessions).

## **Procedure**

Potential participants who met the inclusion criteria were identified by their clinician and given an information sheet (Appendix H). Those who were interested in participating completed a 'consent to contact' form (Appendix I), which was passed to the researcher. Twelve CYP completed contact forms, three did not respond to the researcher and one declined participation due to illness. Participants were given the option to attend interviews by telephone, Skype or in person (at home or CFS/ME clinic). Consent and agreement (Appendices J and K) were obtained from all CYP and their parents before taking part in the research.

Interviews were conducted in a flexible manner, following a semi-structured interview schedule (Appendix L). The interview schedule was initially developed through consultation with the Specialist CFS/ME service whereby the aim of the project and important areas of questioning were considered. It was agreed the schedule should be specific to each group (actively attending, attended then declined and declined Skype) and include the following topics; decisions to use, decline or stop using Skype, experiences of using Skype, thoughts about why CYP do or do not want to use Skype to attend appointments and suggestions about how to improve Skype. Changes were made to the interview schedule to address gaps and facilitate a richer exploration of the topic as the research progressed; previous interviews were iteratively used to inform subsequent stages of data gathering. For example, as CYP spoke about their environment and location when using Skype, this became a prompt on the interview schedule. Interviews lasted between 15 and 35 minutes.

Interviews were audio recorded and transcribed verbatim. All personal identifiable data was removed to ensure anonymity. This study was deemed to fall within the remit of service evaluation and did not require full NHS ethics permission. It was reviewed and approved by the relevant Research and Development department, and the Department of Psychology Ethics Committee at the University of Bath (Reference Number 16-013).

## **Data Analysis**

The data was analysed using thematic analysis (Braun & Clarke, 2006). All coding was done manually by annotation, hand-drawn maps and tables using Microsoft Word.

Themes within this research were identified on the semantic level and therefore the analysis was underpinned by an essentialist/realist framework which aimed to report on the experience, meaning and reality of participants (Braun & Clarke, 2006). Although the lead researcher held a relatively neutral position to the data as they did not work in the CFS/ME service and had never used videoconferencing to conduct therapeutic sessions,



the researcher was aware of potential implicit biases due to previous experiences of videoconferencing in their personal life. In order to reduce potential impacts on data analysis, three transcripts were randomly selected and second coded by an independent researcher. There was close agreement between researchers when coding was reviewed.

## Results

The coding scheme included three main themes and eight sub themes (Appendix M). Each theme is presented and supported by verbatim excerpts.

### **‘A different connection’: Therapeutic Experience and Engagement**

The first theme refers to the CYP’s experiences of using Skype and their subjective sense of connection with the therapist in the context of communicating through a screen.

**Therapeutic engagement.** The majority of participants were able to build good rapport over Skype and for some, it helped them to be more open in therapeutic sessions as they found it less intimidating:

*It’s sometimes easier to say it through a screen than it is to a person, so I think certain things are easier to talk about... I think it’s the fact that it’s not a person like sitting in front of you, it’s through a screen, it’s not as intimidating. (Rachel).*

However, seeing a clinician through a screen was also described by some as a potential barrier to therapeutic engagement by occasionally limiting body language, restricting emotional expression and reducing eye contact. Physical presence was seen as more important if the CYP were dealing with particularly sensitive material:

*Sometimes you might be [in] a situation where you actually want to be with that person because there is a different connection over Skype... it might be that you feel like you need to be with the person. (Samantha).*

**Therapeutic experience.** Participants described the therapeutic experience through Skype positively and commented on how similar face-to-face and Skype sessions could be:

*I’ve been surprised at how personal the appointments still are, you do still feel like you can talk and it shouldn’t make a difference it’s a screen... the experience has been positive. (Anna).*

One participant who had declined to use Skype described it as ‘the next best option’ if they were unable to attend face-to-face appointments due to a lack of specialist service in their area.

Skype appeared to reduce stress associated with the therapeutic experience:

*It is more relaxed, it doesn't feel like you're at an appointment.... a lot of the stress and the anxieties around going out and doing appointments goes away I think. (Rachel).*

Whereas another participant believed that in order to make changes in treatment, sessions should retain an element of stress to reflect difficult content, and wondered if this might be lost over Skype:

*The actual appointment itself would probably be less tiring, but then would you actually be getting to the bottom of it, it's part of the treatment it's meant to be a bit emotionally wearing you're meant to be working hard at it. (Tom).*

### **'It was a little chaotic, but it was ok': Anticipations, Preparations and Technology Use**

The second theme detailed the anticipatory anxieties participants held about using Skype, preparations they made to reduce their anxieties and their experiences of using the technology involved.

**Easing anticipations by preparing for Skype.** Many participants expressed anticipatory anxieties about using Skype. However, after experiencing Skype, all but one said it exceeded their expectations:

*It is quite different from seeing someone in person but I thought it was actually better than I thought it was going to be ... I thought it would be a bit kind of impersonal but actually it wasn't. (Samantha).*

Several participants expressed confidentiality concerns impacting the information they shared:

*The fact that mum and dad were in the house it seemed that it did restrict me on telling information at some points. (Jacob).*

Participants made suggestions for how to ease their anxieties. For example, making a practice Skype call before the first appointment to check the technology.

The assumption that CYP have pre-existing knowledge about Skype was a potential barrier:

*We didn't actually have Skype on the computer ... there was a little bit of a gap there, it was a little bit of oh well everybody knows how to use Skype assumption. (Anna).*

It was suggested that providing more information before starting Skype in the form of a video recording or a leaflet would be helpful.

Some participants wanted to have an initial face-to-face appointment in preparation for transitioning to Skype, and they suggested that if this was not available the therapist could offer an introductory telephone call.

**Using the technology.** All participants discussed technical issues associated with Skype. These included issues with connection speed, quality of the picture and sound quality, all leading to disruptions to the session:

*We got cut off like 3 times, so it took longer than an hour for the actual appointment ... we did finish it in the end but it did take a while because we had to call her back again. (Emily).*

Despite this, seven out of eight participants were tolerant of technical issues and had their own strategies to overcome these, like reconnecting, or using the telephone.

Additionally, for some who also described negative technical experiences, they also described positive technical experiences:

*I mean the first time we had the first one it took a little while for us to get it working but ever since then it's been perfectly fine, it sorted out and it works really well now. (Rachel).*

Several participants made suggestions for improvements to the technology; investigating the use of screen sharing to aid the exchange of information, trialing a different platform than Skype to reduce technical issues, using a mobile phone app to improve eye contact and investment in a high quality webcam and microphone.

**Sharing resources.** Most participants discussed the process of sharing resources over Skype. Face-to-face, participants were often given formulation diagrams, information leaflets, activity diaries etc. to read or complete. This did not appear to be as easy over Skype:

*There are some times when they want to draw something, that probably is the downside... yes you can send them but you might want to be reading them and here you can have a quick look and ask a question. (Lily).*

However, the CYP reported it was possible to overcome these difficulties; many of the participants were happy to receive leaflets in the post or by email, and one participant found the service website to be an important resource:

*We got them [leaflets] at the first appointment, but also since then we've been sent like things ... little booklets and sheets and also the website as well you can actually download... It's a great website actually. (Rachel).*

### **‘It was way easier to access’: Accessibility and the Impact of CFS/ME Symptoms**

The third theme describes how Skype improves access to evidence-based therapies, how it can negatively and positively impact CFS/ME symptoms and how it reduces the disruption attending treatment can have on CYP’s lives.

**Improving access.** Skype improves access to evidence-based therapies for CYP who are either too unwell or live too far away to receive a specialist service:

*Now I feel totally supported I mean even like my actual ME has improved so much since I’ve been actually using the service that if I wouldn’t have been able to access it and still be where I was say a year ago. The service has just helped so much and we wouldn’t have been able to do that without Skype. (Rachel).*

Participants suggested that Skype should be prioritised for CYP who struggle to leave the house due to their symptoms or who live especially far away, resulting in high financial cost and physical burden of travelling for the CYP and their families. Skype also reduced cancelled appointments as it allowed some participants to attend when they would otherwise have been too unwell to travel to the clinic:

*You don’t have to cancel appointments even if you’re feeling rough and you can’t get to hospital; you might have enough energy to sit in front of laptop and then it might be quite useful as well for people to see how poorly you are. (Anna).*

**Mutual impact of CFS/ME symptoms.** Skype appeared to reduce the impact of having CFS/ME and its treatment on the lives of the CYP by ‘fitting’ into their day, compared to planning their day around travelling to and attending clinic. For some, the burden of travelling to appointments could result in physical and mental payback that could affect their school attendance and attainment:

*If I was going out for a day or just going out to do an appointment, I wouldn’t be able to get to school and stuff because I would be too tired and this way I can get all my schoolwork done and I can get the appointment done and do everything else I need to as well. (Rachel).*

Some participants reported that using Skype can also have a positive impact on CFS/ME symptoms and the quality of the session:

*I actually think you have a better appointment because you aren’t so tired you can’t think straight. (Samantha).*

However, some participants also noted that their CFS/ME symptoms interfered with their ability to focus during Skype sessions; use of screens impacted their ability to concentrate, although they also acknowledged similar difficulties face-to-face.

**In control of environment.** The use of Skype appeared to appeal to the majority of participants because it allowed them to access treatment from the comfort of their own homes. Being in their own home appeared to help participants feel relaxed, in control of their own environment and more able to share important information with their therapist that they felt they might not be able to do face-to-face.

*You're in your own house as well, yeah you're more in your element and you've got your own space. (Emily).*

## **Discussion**

The CYP interviewed felt they were able to therapeutically engage with evidence-based treatment using Skype whilst remaining aware of a 'different connection'. Although participants valued face-to-face appointments, Skype was consistently described as 'as good as' or the next best thing, especially when illness severity and distance were barriers to accessing treatment. This is consistent with findings reported by Grealish et al. (2005) when exploring videoconferencing in a CYP mental health service.

Technological issues could affect how the CYP experienced Skype appointments; previous findings suggest when Skype technological issues are present, more energy could be spent on the technology rather than on the conversation with the child (Simeonsdotter Svensson et al., 2014), highlighting the need for an easy-to-employ contingency strategy to reduce session disruption. Nevertheless, many participants were relatively accepting and accommodating of technology issues when they were brief or infrequent.

The use of Skype appears to address four factors identified by Fisher and Crawley (2012) in their study examining why CYP with CFS/ME feel anxious. Firstly, Skype appears to facilitate rather than impair CYP's lives. CYP with CFS/ME consider being part of their peer group important and Skype appears to reduce the burden of attending treatment therefore allowing them to remain in school or to choose to use their energy on more enjoyable or social activities. Secondly, completing school work was described as a significant worry as many of the CYP miss large amount of school due to non-attendance. Skype commonly allowed CYP to remain in school and complete their work without the additional pressure of travelling to appointments. Thirdly, CFS/ME can impact the whole family and some CYP can feel as though they are a burden on family resources, leading to feelings of guilt. CYP who are unwell rely on family members for emotional and practical support, limiting their age-appropriate independence. The CYP in this study were acutely aware that Skype significantly reduced burden on family resources. Skype also allowed the CYP to feel more in control of their treatment as they could independently access Skype from the comfort of their chosen environment. This is similar to existing research

examining Skype in paediatric settings, whereby a sense of taking responsibility and exerting control over the appointment have been key themes (Boydell, Volpe, & Pignatiello, 2010; Grealish et al., 2005).

### **Limitations**

This study is based on the experiences and opinions of a small number of participants from one specialist paediatric CFS/ME service and therefore, may not necessarily be assumed to be representative of all CYP with CFS/ME. Furthermore, although data saturation was reached when examining the dataset as a whole, it might have been more meaningful for data saturation to have been met within the three distinct groups of participants. This was currently not achievable due to the novel use of Skype within the service and may have limited a full exploration of the topic due to the findings based predominantly on the views of CYP who were actively using Skype. Further exploration is needed with participants who have declined to use Skype or have used Skype and then stopped to gather a richer understanding of this topic. Additionally, the study this study did not include parent or clinician perspectives.

### **Recommendations to the CFS/ME Service and potential improvements**

The findings were initially fed back to the Clinical Lead for the paediatric CFS/ME service. Subsequently, a PowerPoint presentation summarising the findings of this study was presented and discussed with the Specialist Paediatric CFS/ME Service at a clinical team meeting in March 2017. A series of recommendations (Appendix N) was made to the team about how they could improve on their use of Skype, based on these findings. The team commented on their own experiences of using Skype with CYP and agreed with the themes identified in this study. They felt further research that took into account parent and clinician perspectives would be a useful next step in this research, and are seeking funding to further this important work. The team agreed that they would implement the recommendations made by this service improvement project when using Skype and the PowerPoint presentation and a three-page summary of the research were circulated to the team for future reference. The authors also prepared a draft Skype information leaflet (Appendix O) with help from the team as outlined in the recommendations of the study that the service could give to CYP and their families when considering Skype.

### **Conclusion**

CYP with CFS/ME can overcome potential barriers to therapeutically engage with evidence-based treatment through the use of Skype, albeit with a sense of ‘different

connection'. Although the CYP still valued face-to-face appointments, attending Skype sessions from their own homes had multiple benefits; it reduced the burden of travel for themselves and their families, reduced the amount of time they missed from school and gave them more control over their environment. Skype appears to be a valuable and acceptable form of service-delivery, especially when CYP live a considerable distance from a specialist service.

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**Discussing Disclosure: A Mixed Method Exploration of Disclosing Mental Health Problems**

Candidate: Charlotte Whittle

Supervisor: Lorna Hogg

Target Journal: Stigma and Health (Appendix P)

*This journal was chosen due to its relevance to the research project*

**Current word count: 6,211**

## Introduction

Disclosing mental health problems is a process that calls for careful reflection and preparation by individuals to decide why, how and to whom they disclose (Korsbek, 2013). Korsbek (2013) identified that important benefits of disclosure can be classified on two levels; societal and personal. At the societal level, contact with people with mental health difficulties can create positive changes in attitudes towards mental health (Rüsch, Evans-Lacko, & Thornicroft, 2012). Therefore, disclosing mental health problems is regarded as vital in local, national and global anti-stigma campaigns.

At the personal level, there is mixed evidence for the positive effects of disclosure. Research exploring adolescent's experiences of disclosure suggested that although some experienced negative reactions that impacted future disclosure-decisions, benefits far outweighed costs (Buchholz, Aylward, McKenzie, & Corrigan, 2015). Additionally, whilst disclosure is vital in order to access services and support, a qualitative study investigating stigma amongst six participants with a diagnosis of schizophrenia reported how they commonly experienced prejudice as a result of help-seeking (Knight, Wykes, & Hayward, 2003) and a recent systematic review identified that disclosure concerns were the most commonly reported stigma barrier to help-seeking (Clement et al., 2015).

Previous literature has tended to focus on disclosure in relation to help-seeking and in occupational contexts but research has not paid due attention to disclosure as fundamentally social (Rice, Comulada, Green, Arnold, & Rotheram-Borus, 2009). However, there has been a recent shift in the literature to examine disclosure in social relationships (e.g. Pahwa, Fulginiti, Brekke, & Rice, 2017). Selective disclosure appears to be the preferred strategy for many, with people carefully considering whom they disclose to, opting for friends, partners and family rather than acquaintance and colleagues to maximise social support whilst minimising potential stigma and discrimination (Bos, Kanner, Muris, Janssen, & Mayer, 2009). Additionally, positive experiences of disclosure may help individuals process their mental health experiences and integrate these experiences into their sense of self (Corrigan & Matthews, 2003). However, disclosure can take many forms and in addition to voluntary disclosures, people with mental health problems may also experience involuntary disclosures. Involuntary disclosures can take different forms but tend to focus on two mechanisms; an individual sharing this information without permission from the discloser and disclosure through displays of behavioural symptoms, hospitalisation, absence from routine activities etc. (Chen, Lai, & Yang, 2013). Having supportive social relationships in which individuals can share and process difficult experiences, including mental health problems, are important for general health and well-being (Thoits, 2011). However, studies examining confidants in first-

episode psychosis have found that a third of individuals did not have a social relationship in which they felt able to disclose (Sündermann, Onwumere, Kane, Morgan, & Kuipers, 2014) and were seven times more likely not to have a confidant than the general population (Morgan et al., 2008).

### **The impact of stigma**

Individuals may find it particularly difficult to make disclosure-decisions due to the significant and harmful impacts of stigma. Stigma refers to the prejudice and discrimination that emerges when the general population endorse specific negative stereotypes. Additionally, self-stigma refers to the internalisation of public stigma and the application of negative stereotypes to the self (Corrigan & Watson, 2002) which can have serious negative impacts on self-esteem and self-efficacy (Corrigan, Watson, & Barr, 2006). This has been conceptualised as the ‘why try’ effect (Corrigan, Larson, & Ruesch, 2009), which suggests that low self-esteem and self-efficacy, due to self-stigma, dissuades people from pursuing opportunities that are fundamental to achieving their life goals and personal recovery. The ‘why try’ effect is based upon Modified Labelling Theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) which suggests people develop a set of beliefs about how others will respond to those with mental health problems. When an individual has a mental health problem, the more they believe they will be devalued and discriminated against, the more stressed they will feel about interacting with others, which may prevent them from disclosing to others for fear of negative consequences or rejection. It is proposed by the theory that fear of rejection and inadequate coping strategies to respond to stigmatising reactions may have a serious negative effect on the individual’s ability to access and receive social support.

Mental health problems can carry significant social stigma which may also increase the risk of self-stigma (Corrigan & Kleinlein, 2005), with experiences of bipolar disorder (Day, Edgren, & Eshleman, 2007; Hawke, Parikh, & Michalak, 2013), personality disorders (Knaak, Szeto, Fitch, Modgill, & Patten, 2015; Sheehan, Nieweglowski, & Corrigan, 2016; Veysey, 2014) and schizophrenia and psychosis (Angermeyer & Dietrich, 2006; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Griffiths et al., 2006) commonly regarded in the literature as significantly more publically stigmatised mental health problems compared to others.

To reduce the risk of encountering stigma, many choose to conceal their mental health difficulties. Rosario, Hunter, Maguen, Gwadz, and Smith (2001) report that keeping an important aspect of life secret can have a negative impact on quality of life and therefore keeping mental health issues a secret may lead to isolation and reduced social

support (Thornicroft, 2006). Individuals who choose to conceal their mental health problems due to stigma can become concerned that their displays (e.g. non-verbal behaviour) ‘give them away’ and their continual efforts to conceal can increase intrusions and anxiety in social encounters, leading to increased avoidance and withdrawal (Smart & Wegner, 1999).

Corrigan et al. (2010) suggest that people who choose to disclose their mental health problems experience less negative impacts of self-stigma on their quality of life by developing strategies to externalise the self-stigma. The current literature on disclosure tends to suggest being open about mental health problems can facilitate life goals.

### **The paradox of disclosure**

To be able to access social support, individuals must do precisely what may generate stigma and discrimination; disclose their mental health problems. In other words, individuals must take the risk of being met with stigmatising reactions in order to gain support to help deal with them. Therefore, individuals who are in a position to conceal their stigmatised identity may feel like they are constantly faced with the difficult decisions of disclosure or concealment.

Frable, Platt, and Hoey (1998) compared concealable and visible stigmas and found those with concealable stigmas had higher anxiety, depression and lower self-esteem than those with visible stigmas. Individuals with a visible stigma may experience less psychological difficulties than those with a concealable stigma because they may have access to an array of possible coping strategies, including more access to social support and upwards comparisons to in-group members (Quinn, 2006).

Individuals disadvantaged in multiple ways (e.g. belonging to more than one discriminated group) face greater exposure to discrimination than their advantaged or singly disadvantaged counterparts. This seems to have a cumulative effect; experiencing multiple forms of discrimination is associated with poorer mental health relative to one factor of discrimination alone (Grollman, 2014). This phenomenon is described in the literature as *intersectionality* (Crenshaw, 1991) and refers to the impact of multiple identities and forms of prejudice on experiences of inequality. Therefore, individuals who have a mental health problem and an additional stigmatised identity (e.g. a disability) may experience more disclosure-stress.

Rusch, Brohan, Gabbidon, Thornicroft, and Clement (2014) found that anticipated discrimination by others, combined with the perception that one’s coping resources are insufficient, may lead to people feeling less comfortable disclosing their mental health

issue to friends and family. This anticipated future discrimination appeared to have a greater impact on disclosure-decisions than actual discrimination experienced in the past.

Individuals with mental health problems frequently encounter situations where they need to make a decision about whether they conceal or disclose their mental health problems to others. Disclosure may lead to positive outcomes such as increased support or it might lead to negative outcomes such as discrimination and rejection. However, concealment may also lead to positive outcomes such as protection from prejudice, or negative outcomes such as reduced help-seeking and increased public stigma. Due to the potential stress some people may experience around disclosure, our research aims were to adapt an existing questionnaire in order to measure disclosure-stress and to identify factors which may influence disclosure-stress. We developed our primary hypothesis based on previous literature: higher disclosure-stress will be associated with higher self-stigma, lower well-being, lower social support, lower numbers of disclosure, less satisfaction with number of disclosures and belonging to more than one stigmatised group (e.g. sexual orientation, health condition/disability, ethnicity).

We used a mixed-method approach to collect rich data in order to make recommendations to provide interventions and support for individuals so they can reduce stress around making personal, contextual disclosure-decisions.

## **Method**

The quantitative methodology will be described first, followed by the qualitative methodology.

### **Quantitative**

**Participants.** A sample of participants who self-identified experiencing a mental health problem were recruited via online advertisement and social media. Participation was completely voluntarily and required informed consent. Demographic characteristics for all participants (N = 831) are summarised in Table 1 below. Due to removal of outliers and missing data points the total number of participants varies between analyses.

Table 1. *Demographic characteristics of participants (N=831)*

	N/Mean(SD)	%
<b>Gender</b>		
Female	761	91.6%
Male	25	3.0%
Transgender	8	1.0%
Other	9	1.1%
Missing data	28	3.4%
<b>Age</b>	30.15 (9.75)	
<b>Sexuality</b>		
Heterosexual	503	60.5%
Homosexual	48	5.8%
Bisexual	120	14.4%
Asexual	8	1.0%
Pansexual	14	1.7%
Other	11	1.3%
Missing data	127	15.3%
<b>Ethnicity</b>		
White	785	94.5%
Mixed	16	2.0%
Black	6	0.7%
Asian	10	1.1%
Other	12	1.4%
Missing data	2	0.2%
<b>Place of residence</b>		
UK	767	92.3%
Other Europe	8	0.9%
North America	24	2.8%
Australia and New Zealand	6	0.8%
India	4	0.5%
Other	3	0.3%
Missing data	18	2.2%
<b>Number of mental health problems (self-identified)</b>	3.55 (1.94)	
<b>Primary mental health problem (self-identified)</b>		
Depression	359	43.2%
Schizophrenia/psychosis	10	1.2%
Bipolar/Mania/Manic depression	66	7.9%
Panic Disorder	14	1.7%
Specific Phobia	4	0.5%
Generalised Anxiety Disorder	135	16.2%
Obsessive compulsive disorder	20	2.4%
Hoarding	1	0.1%
Social anxiety	20	2.4%
Post-traumatic stress disorder	44	5.3%
Health anxiety	4	0.5%
Persistent physical symptoms	2	0.2%

<b>Dissociative Disorder</b>	2	0.2%
<b>Anorexia Nervosa</b>	22	2.6%
<b>Bulimia Nervosa</b>	9	1.1%
<b>Other eating disorder</b>	11	1.3%
<b>Personality disorder</b>	85	10.2%
<b>Other</b>	19	2.3%
<b>Missing data</b>	2	0.2%
<b>Disability/Long-term health condition</b>		
<b>Yes</b>	177	21.3%
<b>No</b>	630	75.8%
<b>Prefer not to say</b>	24	2.9%

**Materials.** Participants completed all questionnaires described in Table 2.

Table 2. *Questionnaires completed by participants.*

<b>Measure</b>	<b>Details</b>
<b>Average number of disclosures and satisfaction measure (ANDS)</b>	This measure asked participants to report how many people they had disclosed their mental health difficulties to on a 7-point Likert scale in certain domains of their life; close family, extended family, friends, work colleagues, people at their education facility and health professionals. Participants were also asked to rate how satisfied they were with that number of disclosures (i.e. their satisfaction with the amount of people they had told in that domain, rather than the specific disclosure experience) on a 5-point Likert scale. An average score was taken across domains to produce an number of disclosures score and a satisfaction of number of disclosures score.
<b>The Cognitive Appraisal of Disclosure as a Stressor (CADS)</b>	This is an 8-item questionnaire that has been adapted from frequently used stress appraisal questionnaires (e.g. (Rüsch, Corrigan, Wassel, et al., 2009) (Rüsch, Corrigan, Powell, et al., 2009) (C. R. Kaiser, Major, & McCoy, 2004; Tomaka, Blascovich, Kelsey, & Leitten, 1993)) to measure the amount of stress individuals experience about disclosing their mental health problems to others. Four items assess the primary appraisal of disclosure as potentially harmful and four items assess the secondary appraisal of perceived resources to cope with disclosure. A single stress appraisal score is calculated



	(between -24 and 24) by subtracting perceived resources to cope from perceived harmfulness. Higher scores indicated higher disclosure-stress.
<b>Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, &amp; Farley, 1988).</b>	This is a 12-item measure that records responses on a 7-point Likert scale. This measure is used to assess the extent to which people perceive support from their family, friends and a significant other. Cronbach's alpha = .88; Test-retest = .85; Construct validity = the MSPSS was significantly negatively related to depression ( $r = -.25$ , $p < 0.1$ ).
<b>Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) (Tennant et al., 2007).</b>	This is a 14-item scale that aims to assess subjective wellbeing and psychological functioning. Cronbach's alpha = 0.91; Test-retest = .83; Construct validity = the WEMWBS was significantly negatively correlated with the General Health Questionnaire ( $r = -.53$ , $p < 0.01$ ).
<b>The Self-Stigma of Mental Illness Scale – Short Form (SSMIS-SF) (Corrigan et al., 2012).</b>	This is a 20-item measure that examines the extent to which individuals are aware of negative stereotypes about mental health and the extent to which they apply these attitudes to themselves. Cronbach's alpha = awareness scale .87; agreement scale .79; application scale .69; harm scale .76.

**Procedure.** The study was advertised through social media using an Instagram account and Facebook page to post and promote recruitment posters. Recruitment took place within the community so as not to discriminate against potential participants who were not at the stage of help-seeking. Potential participants clicked on the link for the study and were taken to the information sheet (Appendix Q). Participants were then required to provide informed consent (Appendix R) before completing the questionnaires (Appendices S-X). Measures were administered via an online survey system, Bristol Online Surveys, powered by the University of Bristol (<http://www.survey.bris.ac.uk/>). All participants were debriefed via a debrief form (Appendix Y).

The mixed methods study was approved by the University of Bath Ethics Panel, reference 16-227. All participants gave informed consent to participate and participation was entirely voluntary.

## **Qualitative**

**Participants.** Twelve participants were recruited from the quantitative element to take part in qualitative interviews (7 female, 5 male). Data saturation was reached after the tenth participant and continued for the final two. This was a sample of convenience as the first seven women and first five men who consented to take part were recruited (an additional six participants consented to take part but did not reply to invitations to arrange an interview). All the participants described themselves as having a relatively open stance to disclosure and eight identified working in professions associated with healthcare, academia or psychology.

**Procedure.** Potential participants were required to read the information sheet (Appendix Z) and informed consent was obtained from all participants (Appendix AA). Interviews were conducted by telephone following a semi-structured interview schedule (Appendix AB). The interview schedule began with an initial question about participants' stance on disclosure. Following topics included, experiences of disclosure (e.g. can you describe any positive experiences of disclosure?), experiences of non-disclosure or secrecy (e.g. has there been a time when you have thought it was better not to disclose in a situation?), views on society (e.g. what is your opinion of disclosure campaigns?), qualities of person identified for disclosure (e.g. would any qualities make it more or less likely for you to disclose?), telling your story (e.g. are you aware of any language you use to talk about your experiences?), disclosure goals (e.g. what do you hope to achieve when choosing to disclose?), experiences of social support (e.g. how does disclosure impact social support?) and experiences of self-stigma (e.g. do you feel self-stigma impacts on your decision to disclose or not?). Interviews lasted between 35 and 55 minutes. Changes were made to the interview schedule to address gaps and facilitate a richer exploration of the topic as the research progressed. Interviews were audio recorded and transcribed verbatim. All personal identifiable data was removed to ensure anonymity.

## **Data Analytic Strategy**

**Quantitative.** Firstly, due to the use of the newly adapted measure of the CADS, we examined its psychometric properties; including a factor analysis, test-retest and internal consistency. Secondly, in order to test our primary hypothesis, we performed a stepwise regression. Missing data and outliers were removed from all continuous variables resulting in a final sample of seven hundred and seventy-two participants (N=772).

**Qualitative.** The data was analysed using thematic analysis (Braun & Clarke, 2006). The data analysis programme Nvivo was used to identify codes. Themes within this research were identified on the semantic level and therefore the analysis was underpinned by an essentialist/realist framework which aimed to report on the experience, meaning and reality of participants (Braun & Clarke, 2006). The lead researcher identified as having experience of a less publically stigmatised mental health problem and was aware of the potential impacts this may have had on data analysis. Therefore, to reduce potential impacts of implicit bias, three transcripts were randomly selected and second coded by an independent researcher. There was close agreement between researchers when coding was reviewed and discrepancies in coding were addressed and refined.

## **Results**

### **Quantitative**

#### **Psychometric properties of the cognitive appraisal of disclosure as a stressor scale.**

**Factor analysis.** A principal component factor analysis was conducted on the 8-items with varimax rotation (N=808). The Kaiser-Meyer-Olkin measure was .899, indicating that the correlation matrix was adequate for analysis (Kaiser, 1974). Bartlett's test of sphericity was significant, indicating that factor analysis was suitable (Bartlett, 1954). Additionally, factor analysis was deemed appropriate with the dataset (N=808) as Kass and Tinsley recommend five participants minimum per item (Tinsley & Kass, 1979).

Two factors were retained which together explained 76.69% of the variance, this was consistent with the scree plot. A qualitative review of the items indicated acceptable coherence in construct. The item clustering confirmed that factor one represents the primary appraisals of disclosure as potentially harmful and factor two represents secondary appraisals of perceived resources to cope with disclosure. All eight items were retained.

**Test-retest reliability.** Data was gathered at a second time point one to two weeks after the first completion from a sub group of participants (n = 127). This subgroup was selected as a sample of convenience, being the first 127 participants to complete the measures twice within the allotted time. Correlations between the test and retest scores were analysed using Pearson's r (0.89) and indicated good reliability (Figure 1.).

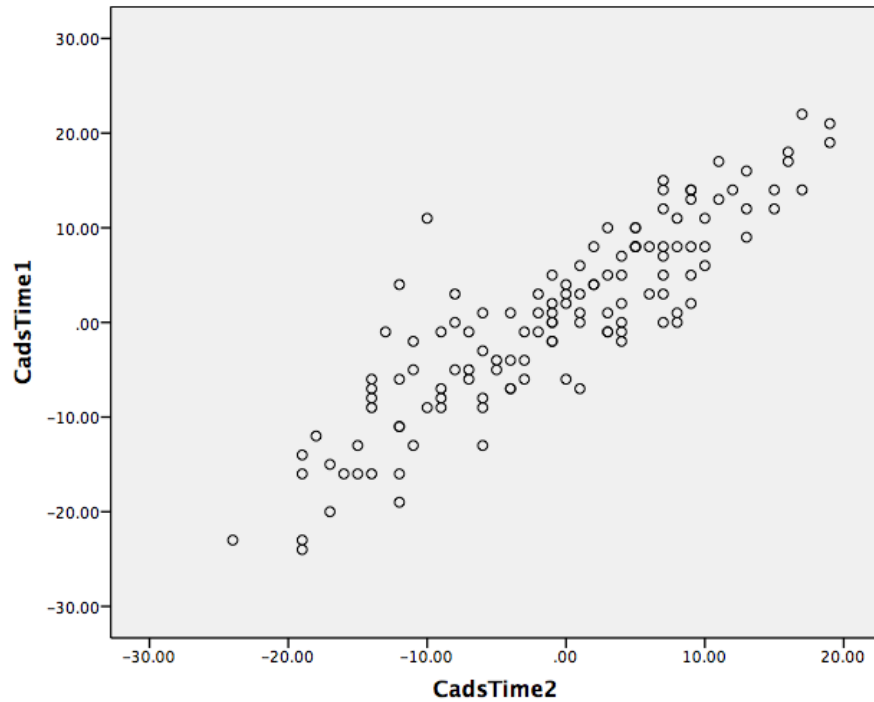


Figure 1. Correlation of the CADS at time 1 and time 2.

**Internal consistency.** The CADS was found to have high overall reliability (internal consistency) at Cronbach's  $\alpha = .91$ . The primary appraisals of disclosure as potentially harmful ( $\alpha = .92$ ) and the secondary appraisals of perceived resources to cope with disclosure ( $\alpha = .85$ ) both showed good reliability.

**Primary analysis: Association between disclosure-stress and independent variables.** The primary purpose of this investigation was to investigate whether higher disclosure-stress was associated with higher self-stigma, lower well-being, lower social support, lower numbers of disclosure, less satisfaction with number of disclosures and belonging to another stigmatised group (e.g. sexual orientation, health condition/disability, ethnicity).

**Multiple regression.** The dependent variable (CADS) and the independent variables, (Number of disclosure scores, satisfaction with number of disclosures scores, MSPSS scores, WEMWBS scores, SSMIS-SF scores, and demographic variables; age, sex, sexuality, ethnicity, disability/long-term health condition status) were entered into a stepwise linear multiple regression. Tests for multicollinearity indicated multicollinearity was not an issue; the data met the assumption of independent errors (Durbin-Watson value = 2.06); the histogram of standardised residuals indicated that the data contained normally distributed errors, as did the normal P-P plot of standardised residuals and the scatterplot of

standardised residuals showed that the data met the assumptions of homogeneity of variance and linearity.

Table 3. *Summary of stepwise linear multiple regression analysis for variables associated with disclosure-stress (CADS scores) (N = 772).*

		$\beta$	R <sup>2</sup>	R <sup>2</sup> change	F value	Sig.
<b>Model 1</b>	Wellbeing (WEMWBS)	-.445	.198	.198	189.818	p<0.001
<b>Model 2</b>	Wellbeing (WEMWBS)	-.382	.324	.127	184.601	p<0.001
	Number of disclosures	-.361				
<b>Model 3</b>	Wellbeing (WEMWBS)	-.330	.366	.041	147.679	p<0.001
	Number of disclosures	-.271				
	Satisfaction with disclosure number	-.232				
<b>Model 4</b>	Wellbeing (WEMWBS)	-.236	.403	.037	129.494	p<0.001
	Number of disclosures	-.282				
	Satisfaction with disclosure number	-.222				
	Self-stigma (SSMIS-SF)	.216				
<b>Model 5</b>	Wellbeing (WEMWBS)	-.226	.411	.008	107.053	p<0.001
	Number of disclosures	-.285				
	Satisfaction with disclosure number	-.219				
	Self-stigma (SSMIS-SF)	.220				
	Female	.091				
<b>Model 6</b>	Wellbeing (WEMWBS)	-.188	.419	.007	91.831	p<0.001
	Number of disclosures	-.263				
	Satisfaction with disclosure number	-.197				
	Self-stigma (SSMIS-SF)	.214				
	Female	.100				
	Social Support (MSPSS)	-.106				

The first variable to enter was the WEMWBS, accounting for 19.8% of the variance in scores on the CADS. The second variable entered was number of disclosures, which accounted for an additional 12.7% of the variance on the CADS. The third variable entered was the satisfaction with number of disclosures, accounting for a further 4.1% of the variance on the CADS. The fourth variable entered was the SSMIS-SF accounting for an extra 3.7% of the variance on the CADS. The fifth variable entered was female, which accounted for an additional 0.8% of variance on the CADS. Finally, the sixth variable to enter was the MSI, accounting for a final 0.7% of variance on the CADS. All other demographic variables were excluded as they were not significantly associated with CADS scores.

**Additional analysis: Comparison of more publically stigmatised mental health problems and less publically stigmatised mental health problems.** Although not outlined in our a priori data analytic strategy, recruitment for this research far exceeded initial expectations and as a result we were able to perform a second investigation of the data. After recruitment ended, discussion took place within the research team to examine the possibility of additional analysis. As the authors were aware of pre-existing literature examining stigma across diagnoses, we were able to generate an additional hypothesis before completing secondary data analysis: Individuals who have experience of a more publically stigmatised mental health problem will experience higher levels of disclosure-stress and self-stigma and lower levels of social support, well-being, number of disclosures and satisfaction with number of disclosures than individuals who have exclusive experience of a less publically stigmatised mental health problem.

Individuals who had self-identified as experiencing personality disorders, bipolar disorder, schizophrenia and psychosis were grouped into a ‘more publically stigmatised’ mental health problem group according to existing literature (N=260) and all other mental health problems were grouped into a ‘less publically stigmatised’ mental health problem group (N=571). Characteristics of the sample suggested it would be best to compare those who had identified experiencing at least one more publically stigmatised mental health problem, whether they self-identified this as their primary diagnosis or not (N=260), to people who had exclusively experienced one or more, less publically stigmatised mental health problem (N=571).

Those who had experienced at least one more publically stigmatised mental health problem experienced significantly higher disclosure-stress ( $t(806)=2.397$ ,  $p<0.05$ ), higher self-stigma ( $t(812)=5.697$ ,  $p<0.001$ ) and lower social support ( $t(817)=-2.792$ ,  $p<0.005$ ) than those who had not. All findings remained significant after a Bonferroni correction was completed. There were no significant differences in terms of satisfaction with number of disclosures ( $t(829)=-1.562$ ,  $p=0.119$ ) and wellbeing ( $t(822)=-0.632$ ,  $p=0.120$ ) between the two groups. However, when we analysed number of disclosures, people who had experienced a publically stigmatised mental health problem were found to have a significantly higher number of disclosures than those who had not ( $t(829)=3.555$ ,  $p<0.001$ ).

## **Qualitative**

Three core themes were identified in the data; ‘The benefits outweigh the negatives, but it takes some bravery’: Making disclosure-decisions; ‘It’s a skill I have developed over the years’: The art of disclosure, and ‘I think it still needs work’: views on

society and the media. Only the first theme will be described and discussed in this report due to the relevance of this theme to the research aim.

**‘The benefits outweigh the negatives, but it takes some bravery’: Making disclosure-decisions.** All participants described having to make disclosure-decisions that requires weighing up the costs, benefits and potential risks of discrimination and stigmatisation.

***An unspoken connection.*** A persistent theme expressed by all participants was that talking to someone who had also experienced a mental health problem or had a close relationship with someone who had experienced a mental health problem facilitated disclosure. Participants described the greater level of understanding in this social relationship as an ‘unspoken connection’ and helped them to normalise their experience, access social support and feel validated.

*There is definitely greater empathy in talking to someone who has experienced a mental health problem ... the only way I can explain it is that the understanding that they had been in your shoes and you know they had felt something similar it’s kind of an unspoken connection*

***Sense of self-acceptance.*** Disclosure appeared to be facilitated by a greater sense of self-acceptance and this appeared to be associated with a passing of time. For instance, participants described higher levels of self-stigma in the early stages of their mental health problem and wished to distance themselves from diagnoses, however as time passed and participants recovered or had periods of stability in their lives they seemed to become more accepting of their mental health problems and integrated this into their self-identity as someone who can live a fulfilling life alongside their mental health issues.

*I think you have to get to a certain point before you disclose, you have to come to terms with your diagnosis yourself before you can disclose. I think that I became happy with my diagnosis because I could still function even though I had it and that was when I started to be happier disclosing*

***Control of disclosure.*** It is within periods of recovery or stability that it also seems easier for participants to disclose as they feel more in control of their lives and their disclosure. Some participants described feeling out of control of disclosure when experiencing episodes of their mental health problem because their symptoms or treatment meant they involuntarily disclosed to account for behaviours, absences from work, taking

medication etc. Disclosure during an episode appeared to be highly related to self-stigma as participants described being much more self-critical and more likely to interpret reactions more negatively.

*I wonder if part of it is because, a control thing, because I know I'm back in control of it and whether half of it is a pride thing, because to speak to someone at my worst... it just feels so pathetic, just listening to myself, I start getting so angry with myself and that's when the self-criticism comes in*

**Feared Consequences.** Many expressed feared consequences of disclosure and fear of discrimination, especially within a work setting.

*Even though I work for the NHS... you kind of hope and expect that people will have a kind of understanding of mental-health difficulties but there is still that bit of you that feels like I'm going to be judged, I'm going to be discriminated against*

Some participants spoke about wanting to protect others from their disclosure for fear that they would worry.

*I have had suicide attempts in the past and I found that by disclosing... its scared my mum so if I don't reply to a text or a phone call or something instantly she thinks 'oh well she might have done something'*

Participants also reported instances whereby they felt disclosure would change others perceptions of them and they would be treated differently because of their disclosure.

*I wouldn't want them to see me in a different light. I guess because I do handle things quite well... I can seem very, like a normal person and I guess if I disclosed that to somebody, I think they would see me in a different light*

**Experiences of negative responses.** Negative responses to disclosure were reported by participants.

*Peoples responses can be not what you expect... Sometimes you get some very unsympathetic responses or some odd expectation that you can just suck it up and deal with it.*

However, they appeared a less common experience than positive responses due to the careful consideration and strategies participants used to protect themselves from the potential of negative responses.



*I think because I have been quite careful with my disclosure I have built the trust up from [saying] 'I am tired' and usually use the 'I am tired' as a baseline to gauge the reaction and as I learn to trust them I either stick with the 'I am tired' or I reveal the 'I am depressed'*

Additionally, some participants were able to describe how they felt able to 'shrug it off' when they experienced negative or discriminatory reactions from others and in some cases it made participants feel they wanted to disclose to challenge public stigma

*If somebody was being rude about people with mental illness that would make me disclose, that would make me say I've got a mental illness... I would challenge it*

As opposed to overtly negative responses, it actually appeared much more common for participants to describe dismissive responses that appeared to have a significant negative effect on future disclosure-decisions

*They never brought it up again, they never checked in on me, they weren't that bothered about it and in my head when it did get really bad again that year it was like 'oh you know, no one cares' so I didn't tell anyone again.*

***Experiencing disclosure as a man.*** A theme identified by both male and female participants described how participants recognised that making disclosure-decisions appeared more stressful for men than for women due to the added stigma related to socially constructed ideas of masculinity and a 'man up' culture.

*I think there's an even greater stigmatisation with men having mental health issues. Men have to be this systemic strong character... people aren't willing to accept that men can have mental health issues, they treat men differently than they do to women... I was told to 'man up' about it that I was basically told 'shut up, put up and get on with your life'.*

## **Discussion**

This research set out to explore factors which may influence disclosure-stress amongst individuals who have experienced a mental health problem. Minimal literature around mental health disclosure currently exists and this research aimed to develop a scale for measuring disclosure-stress to allow future research to occur. It also examined factors that might be associated with disclosure-stress to better understand disclosure as a stressor in order to provide suitable support to reduce stress so that individuals can feel better placed to make personal, contextual disclosure-decisions.

Quantitative analysis found the CADS to be a reliable measure of disclosure-stress with two factors; the primary appraisals of disclosure as potentially harmful, and secondary appraisals of perceived resources to cope with disclosure. Participants who experienced lower levels of psychological wellbeing, disclosed to fewer people, were less satisfied with how many people they disclosed to, experienced higher levels of self-stigma, were female, experienced less social support significantly appraised disclosure as more stressful (Table 3). However, there did not appear to be an effect of intersectionality; belonging to more than one stigmatised group did not appear to increase disclosure-stress in this study. Additionally, those who had experienced one or more publically stigmatised mental health problems (i.e. a personality disorder, bipolar, schizophrenia and psychosis) experienced significantly higher disclosure-stress, higher self-stigma and lower social support than individuals who had exclusively experienced one or more less publically stigmatised mental health problems. Despite this, people who reported experience of more publicly stigmatised problems actually disclosed their mental health problems significantly more.

Qualitative analysis highlighted how participants regularly made disclosure-decisions by weighing up the potential benefits, costs and risks of the disclosure. Possible benefits seemed to include sharing a connection, increasing social support, normalising their experience and increasing self-acceptance through the process of disclosure. Potential costs and risks appeared to include instances of discrimination, burdening others with worry, unwanted changes to others perceptions of their identity and dismissal by peers. Increased disclosure-stress and self-stigma also appeared to be associated with recent diagnosis, control of disclosure relating to acute episodes of the mental health problem and being male.

Participants with lower wellbeing scores cognitively appraised disclosure as more stressful and this factor was found to have the strongest association with CADS scores (Table 3). Additionally, qualitative interviews identified that participants appeared to find disclosure more stressful when they were experiencing an episode of their mental health problem due to the controllability of the disclosure. Although this research did not directly measure whether participants were currently experiencing mental health problems, lower scores on the WEMWBS indicated lower subjective well-being and psychological functioning and therefore we can hypothesise that participants with lower WEMWBS scores may have been more likely to have been experiencing an episode of a mental health problem. Through triangulation with the qualitative results this may indicate that participants who are currently experiencing an episode of their mental health problem may find disclosure-decisions more stressful than someone who is in recovery.

The findings from this research seem to conflict when it comes to gender; our quantitative findings suggest women find disclosure more stressful whereas the qualitative findings suggest men find it more stressful. Our research appears to reflect mixed findings in the literature regarding gender and disclosure (Brohan et al., 2012; Derlega & Chaikin, 1976; Pahwa et al., 2017). However, the research tends to suggest men find it harder to disclose in social relationships and we suggest the quantitative finding should be viewed with caution due to the significantly higher proportion of women who took part in this study and the possibility of participation bias within the male sample.

In regards to our additional quantitative analysis we had hypothesised that people with more publically stigmatised mental health problems would find disclosure more stressful and therefore disclose less. However, this research found that they actually disclosed more than people with a less publically stigmatised mental health problem. Through triangulation of the quantitative and qualitative findings we could hypothesise the following in relation to our additional quantitative finding: People with more publically stigmatised mental health problems may find it harder to conceal their mental health problem due to the persistence and course of their symptomology. They may then find themselves in more positions when they feel the need to disclose, have instances of involuntary disclosure, or have others disclose on their behalf. They may also have been met with more negative responses than people with less publically stigmatised mental health problems due to increased public stigma around their experiences. This may lead to higher disclosure-stress about future disclosures, more self-stigma as they become more aware of public stigma, and lower levels of social support due to rejection or dismissal from peers.

Our research is consistent with the idea that disclosure is a personal context-specific decision that requires careful consideration of costs, benefits and risks (Korsbek, 2013) and although negative consequences are a reality, the benefits generally outweigh the costs (Buchholz et al., 2015). The findings are consistent with Modified Labelling Theory (Link et al., 1989) and contribute to existing literature examining the role of social support (Garcia & Crocker, 2008) and self-stigma (Corrigan & Rao, 2012; Garcia & Crocker, 2008) in making disclosure-decisions and associated disclosure-stress. Additionally, the findings from the qualitative component of the research provide support for the 'identity development for people with mental illness' model (Corrigan & Matthews, 2003). This model suggests that people with mental health problems navigate a series of stages in order to positively integrate their experiences into their sense of self. In the early stages of their mental health difficulties, they experience identity confusion and compare themselves to others. Similar to the model, within our research, this seemed to

coincide with stronger feelings of self-stigma. However, the model suggests that slowly, individuals learn to accept this new identity and begin to disclose to people they trust in order to access support and seek out others who have had similar experiences. This too, was reflecting in our qualitative findings. Depending on the reactions they receive, fear of negative responses may be replaced by increased acceptance and even pride and some people may become immersed in their new identity. Over time, immersion fades as individuals become familiar with their new identity and this stage is replaced by identity synthesis; their mental health experiences integrate into a wider sense of self.

Interestingly, although our qualitative sample provided rich accounts of disclosure and concealment experiences that ranged from very positive to very negative, all participants described themselves as taking a 'relatively open' stance to disclosure. This may provide a useful insight into disclosure-stress; even those who consider themselves 'open' about their mental health problems can experience significant disclosure-stress in different contexts and different relationships. However, this also highlights possible bias in our qualitative sample as currently the qualitative experience of those who consider themselves to have a 'closed' stance to disclosing their mental health problems remains unknown. This is an area that needs further exploration in order to better understand the phenomenon of disclosure-stress.

Our findings appear inconsistent with findings by Pahwa et al. (2017) who found no relationship between symptom severity or functional level and mental health problem disclosure preference. However, Pahwa et al. (2017) suggest several methodological reasons (e.g. measurement sensitivity, help-seeking sample) that may account for this finding and suggested further research is needed.

This research has several limitations. Firstly, this study utilised a cross-sectional design, and therefore the results are associational, not causal. However, numerous uncontrolled background sources of variance make any causality inferences difficult in field research. This study relied on online self-identified experiences of mental health problems that were not verified diagnostically; this means that two people who reported the same mental health problem may have had dissimilar experiences. However, this can also be the case with two people with the same diagnosis, especially in the case of psychosis. Therefore, this study utilised a community sample so as not to discriminate against those with very minimal numbers of disclosure who were not at the point of help seeking and attending services. However, as a novel measure, it would have also added weight to the research findings if statistical analysis had been performed on the ANDS in order to determine its reliability and validity.

The authors decided not to perform the additional analysis on participant's self-identified primary diagnosis for two reasons; The specific wording of the question appeared to cause some confusion among participants, some misinterpreted it as meaning 'current' mental health problem rather than primary and the exceedingly vast comorbidity of the sample (over 88.4% reported 2 or more mental health problems with an average of 3.55). However, future research might wish to explore this issue further. A further limitation is that this study did not examine the potential impacts of another highly stigmatised condition; substance abuse. Mental health problems and substance abuse are separately highly stigmatised by the public and society (Hinshaw, 2009), but through the process of intersectionality, having a dual diagnosis (a mental health problem and a substance abuse problem) may further impact disclosure-stress and associated factors explored in this research. On reflection, the inclusion of a question related to experiences of substance abuse might have benefited our understanding of disclosure-stress and should be explored by future researchers.

We hope researchers will utilise the CADS measure in future research to further explore issues related to disclosure and expand this much needed area of knowledge. In addition to the associated factors outlined in this research, we believe it may be useful to explore additional factors contributing to the experience of disclosure-stress. For instance, people interviewed for this study suggested being in recovery from their mental health problem, after a long duration of illness, whereby they had integrated a sense of self and identity alongside their mental health problem appeared to be protective against disclosure-stress. Future research is also needed to explore why people who have experienced a more stigmatised mental health problem experience higher disclosure-stress, self-stigma and lower social support but in fact disclose more. It will also be important to further explore the disclosure experiences of men as our findings indicate men might find it harder to disclose mental health problems even in an anonymous research setting.

### **Implications for clinical practice**

This research supports the notion that people who experience mental health problems should be supported to make personal, context specific disclosure-decisions to reduce their experiences of disclosure-stress. Clinicians and services should explore the implementation of group programmes that may reduce disclosure-stress. For example, The Honest Open Proud programme (formerly known as the Coming Out Proud programme (Rüsch et al., 2014)) is an efficacious peer facilitated group that supports people in weighing up the personal costs and benefits and provides people with specific skills to make context-dependent disclosure-decisions. Additionally, this research promotes the use

of peer support to help people talk about their mental health experiences. It is noteworthy that all participants interviewed in this study identified that it would be easier to disclose to someone who they knew had experienced a mental health problem. Peer support may be even more beneficial for those who have experienced a more publically stigmatised mental health problem. As this group may have been met with more publically stigmatising attitudes it may be even harder for them to find a shared connection with someone who understands and can help normalise their experience.

### **Conclusion**

Individuals who experience mental health problems continually make disclosure-decisions based upon assessments of the potential benefits, costs and risks associated with the disclosure. Quantitative and qualitative data identified that some individuals experience disclosure-stress as a result of having to make these decisions about whether to conceal or disclose their mental health problems. Through the triangulation of quantitative and qualitative data we were able to demonstrate that higher self-stigma (possibly related to a recent diagnosis), lower wellbeing (possibly related to experiencing an episode of a mental health problem), lower social support, lower numbers of disclosure, lower satisfaction with number of disclosures and experience of a more publically stigmatising mental health problem are factors associated with higher disclosure-stress. Therefore, individuals who are experiencing these factors may find it more difficult to make disclosure-decisions and may need additional support in order to reduce stress around these decisions. Peer support programmes may be best placed to support individuals as all qualitative participants described how talking to someone who had experienced a mental health problem would facilitate disclosure and reduce disclosure-stress. This research contributes to a much under-researched topic area and sheds light on factors associated with disclosure-stress. However, more research is needed in the future in order to help individuals best navigate the complex journey of disclosure.

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## **Executive Summary of Main Research Project**

Existing literature about mental health disclosure is generally sparse. However, much more attention has been paid to disclosure in help-seeking and occupation contexts rather than social relationships. Nevertheless, recent research has shown that many individuals with mental health problems carefully weigh up the costs, benefits and risks of disclosure in order to maximise positive outcomes and minimise the potential for discrimination and stigmatisation. Having supportive social relationships is generally considered to be very important for maintaining general health and well-being, however, evidence suggests that people who experience mental health problems might find it difficult to talk to others about their mental health problems and access social support. One reason for this might be the impact of public and self-stigma. For example, modified labelling theory suggests that people develop a set of beliefs about how others will respond to those with mental health problems. When an individual has a mental health problem, the more they believe they will be devalued and discriminated against, the more stressed they will feel about interacting with others, which may prevent them from disclosing to others for fear of negative consequences or rejection. It is proposed by the theory that fear of rejection and inadequate coping strategies to respond to stigmatising reactions may have a serious negative effect on the individual's ability to access and receive social support. There also appears to be a sub-group of mental health problems (bipolar disorder, personality disorders and schizophrenia and psychosis) that are significantly more publically stigmatised compared to others.

The paradox of disclosure seems to suggest that in order to be able to access social support, individuals must do precisely what may generate stigma and discrimination; disclose their mental health problems. Therefore, individuals who are in a position to conceal their stigmatised identity may feel like they are constantly faced with the stressful decisions of disclosure or concealment.

Due to the potential stress some people may experience around disclosure, the research aims of this study were to adapt an existing questionnaire in order to measure disclosure-stress and to identify factors which may influence disclosure-stress using a mixed-method design to collect rich data.

A sample of participants who self-identified experiencing a mental health problem were recruited via online advertisement and social media. Eight hundred and thirty-one participants took part in the quantitative analysis and twelve took part in the qualitative analysis. In the quantitative analysis all participants completed measures examining their number of disclosures, satisfaction with disclosure number, disclosure-stress, well-being, social support and self-stigma.

Our findings suggest that individuals who experience mental health problems continually make disclosure decisions based upon assessments of the potential benefits, costs and risks associated with the disclosure. Quantitative and qualitative data identified that some individuals experience disclosure-stress as a result of having to make these decisions about whether to conceal or disclose their mental health problems. Through the triangulation of quantitative and qualitative data we were able to demonstrate that higher self-stigma (possibly related to a recent diagnosis), lower wellbeing (possibly related to experiencing an episode of a mental health problem), lower social support, lower numbers of disclosure, lower satisfaction with number of disclosures and experience of a more publically stigmatising mental health problem are factors associated with higher disclosure-stress. Although the findings need to be considered in light of their limitations (e.g. the reliance on self-reported experiences, cross-sectional design), individuals who are experiencing the factors outlined by this research may need additional support in order to reduce stress around making disclosure decisions. Peer support programmes may be best placed to support individuals as all qualitative participants described how talking to someone who had experienced a mental health problem would facilitate disclosure and reduce disclosure-stress. This research contributes to a much under-researched topic area and sheds light on factors associated with disclosure-stress. However, more research is needed in the future in order to help individuals best navigate the complex journey of disclosure.

## **Connecting Narrative**

Before training, I had always enjoyed undertaking research because I have a real passion for learning and I enjoy viewing an issue from different perspectives. Training has helped me greatly to develop and improve my research skills and I am committed and excited to use these skills in qualified practice. This connecting narrative will provide an overview of the research I have conducted over the past three years and document my processes and reflections whilst completing my main research project, service improvement project (SIP), literature review and case studies.

Whilst considering what might connect my projects, I noticed a clear theme that flows throughout my research: inclusivity. Inclusivity refers to an intention of including people who might otherwise be excluded or marginalised and, although this theme was not intentional, it seems to naturally reflect my passion and values. I spent much of my youth and young adulthood feeling like an ‘outsider’ and I find myself drawn to others who might feel like they are or have been, on the margins of society. In this way, I feel like my initial passion for clinical psychology research may have stemmed from an intense interest and curiosity in people, but through this process, it has developed and evolved into a deeply profound respect for people and I cannot imagine my future career without research in it.

### **Main Research Project**

I will document the progression of my main research project from the conception of the initial idea to the development of the project as it is today. My original idea for my main research project was to conduct a group case series examining the Honest, Open, Proud (HOP) group with young adults who had experienced an episode of psychosis. This idea had stemmed from what felt like a transformative moment I had in my first year of training. I was about to begin a piece of clinical work with a young woman who had experienced an episode of psychosis and decided to read a paper by Tony Morrison to try and help me understand her experience. Reading this paper really helped me understand psychosis from a new, much more normative perspective, but it also made me wonder if I, as a trainee clinical psychologist who had studied and worked in mental health for several years, had struggled to make sense of psychotic experiences, then how must the general population view psychosis? Importantly, this also made me wonder what affect this must have on people who have experienced psychosis, and how it must affect their ability to disclose their experiences to others.

This is when I began to take a research interest in disclosure. A quick scan of the available literature concerning disclosure did not appear to return many results and,

although I initially believed I must have been overlooking a body of literature, I quickly realised that this truly is a significantly under-researched topic area. This is when I came across the HOP programme (originally known as the Coming Out Proud programme). My interest in disclosure was also influenced by an experience I had as an assistant psychologist when I worked with a young adult with an eating disorder who commented that she felt pressured to disclose her mental health problem to others when she did not feel comfortable doing this and what really sparked my interest in HOP was their approach to helping people make their own personal, context-specific disclosure decisions even if that meant non-disclosure. My intentions to examine HOP with young adults who had experienced an episode of psychosis led to a Skype conversation between me, my supervisor (Lorna Hogg) and Pat Corrigan, a world renowned researcher in stigma who developed the programme.

Although HOP had been designed and implemented solely in the United States, Pat was working with the Mental Health Foundation in Scotland to adapt and implement HOP for UK audiences and he proposed that I attended the first HOP peer-facilitator training session later that year. When I attended the training, I was taken completely off-guard by the fact that in order to facilitate the groups, we needed to spend the first day taking part in the group and examine our own disclosure-decisions. Through the process of this research I know I have become much more open about discussing my own mental health difficulties but, at the time, I found the experience rather quite stressful.

Although I was at the point of submitting an IRAS application for the project already described, it was this experience, combined with an awareness of a lack of research examining disclosure as its primary research aim and potential difficulties recruiting young adults from Early Intervention services (as another trainee had been having significant difficulties with her recruitment by this time), that contributed to my decision to change my main research project. This decision also coincided with 'world mental health day' and I was incredibly motivated by seeing a huge number of friends, acquaintances and strangers posting about experiences of mental health problems. I felt curious about the fact that modern society encourages people to disclose, but at the same time, there is very limited research about how people experience disclosure and why for some, it can feel very stressful. This is why I chose to examine factors associated with disclosure-stress for my main research project and I decided to broaden my recruitment strategy to include anyone who self-identified as experiencing a mental health problem as not to discriminate against those who were not at the point of help-seeking and also because the HOP training had highlighted how it was the meaning people attached to their

experiences that was important rather than receiving a diagnosis through attending services.

I have always been really interested in media and advertising, so when advertising the project, I worked hard to create a project 'brand'. The identity of the research focusing on 'Discussing Disclosure', a name that had originated from a discussion with a service-user during my PPE consultation. I was confident from the very beginning of recruitment that if I worked hard with my advertisement I would be able to successfully recruit a large number of participants but I was astounded with how many I managed to recruit in the end. I had a sense that there was an intrinsic motivation for people who experienced mental health problems to want to contribute to society's understanding of mental health problems and reduce stigma. I also got this sense from speaking directly to participants during my qualitative interviews. I was especially passionate about the qualitative element of my research and I have worked hard to retain this element throughout the process. I remember feeling so inspired each time I finished a qualitative interview, and profoundly struck by the sense of respect I had for the participants' stories and experiences that they wanted to share with me in order to help others. This element of the research really seemed to make the whole topic of disclosure come alive and cemented my passion for qualitative research. Although I was only able to report on one theme in my main research project due to the University word count, I hope to include the other themes in my write-up for publication to really give a rich account of people's experiences of disclosure and disclosure-stress. I also hope to continue researching disclosure and stigma in qualified practice.

### **Service Improvement Project (SIP)**

I knew that I wanted one of my projects to be centered around children and young people as this is my long-term clinical interest, so made efforts to secure my SIP in this area. I also really wanted to do a qualitative project that involved speaking directly to children and young people. When the SIP examining Skype in a paediatric chronic fatigue service was suggested by my supervisor (Maria Loades), I was excited to begin work on this project.

It proved more difficult to recruit participants than I had anticipated. I wondered if this was due to the nature of chronic fatigue and added barriers to participation, e.g., potential participants needed to complete a consent-to-contact form. It was also difficult to manage travelling vast distances to complete the interviews if young people wanted to be interviewed in person. Towards the end of recruitment, it seemed most helpful to be based in the same hospital as the CFS/ME team on placement, and I was able to join families in

the clinic after an appointment to complete the interview. If I had more time to recruit, I would have suggested this to more potential participants in order to boost recruitment.

In addition to the themes identified and discussed in the SIP, I am now able to reflect on how it felt speaking to children and young people who were experiencing chronic fatigue. The young people seemed to use language that drew attention to a sense of 'being different' and isolated from others. For example, they frequently used language such as 'but that's just me', and 'I don't know about anyone else'. The way that the young people talked about their experiences of chronic fatigue appeared to highlight a sense of disconnection with other young people, even if they were experiencing similar symptoms. There appeared no group identity shared between the participants and everyone talked of very individualised opinions and experiences, isolated within their own experience of chronic fatigue. I remember discussing this with my supervisor who commented how this reflected her experiences of working with young people with chronic fatigue.

I found it particularly interesting that although I was asking specifically about experiences of Skype, I was also able to also develop my understanding about the experiences and meanings of the young people's chronic fatigue. I also felt very passionate about doing the project in order to help young people better access evidence-based treatments and was especially moved by one interviewee who spoke about how they thought they had only been able to survive chronic fatigue because of being able to access the service by Skype. Because of this, it also felt really clinically relevant and important to make an improvement to the service by developing the leaflet. This project has helped me develop skills, and fueled a passion to continue to perform service improvement in future clinical practice to benefit all service-users.

## **Literature Review**

Following on from my interest in qualitative methodologies, I knew I wanted to complete a literature review examining qualitative research. I initially intended to complete a meta-synthesis examining family perspectives on caring for young people with an eating disorder based on my observations in my previous role as an assistant psychologist. However, as I began my systematic literature search, I came across a recent review article concerning this exact topic. I therefore needed to think of another literature review idea. I had just finished my learning disability placement and had noticed a theme of sexuality that had run through all of my cases in some way or another. When looking at the published research there seemed enough qualitative research had been published concerning sexuality in people with learning disabilities but that this had not yet been synthesised. I also felt quite passionately about performed this meta-ethnographic

synthesis as instead of prioritising the voices of people with learning disabilities, the only meta-synthesis concerning sexuality in the lives of people with learning disabilities had prioritised the voices of carers.

I do not think I had quite anticipated what a demanding piece of work the meta-ethnography would be and it required a huge amount of time and effort to complete. Despite this, I also found it hugely rewarding and enjoyable as, based on my experiences, it felt very clinically relevant to make recommendations that would allow services to better support people with learning disabilities express their sexuality. It was a really interesting experience quality assessing the articles as I think it has helped me to become a better qualitative researcher by knowing what needs to be reported and considered in order to produce a high quality qualitative research article. Having the Coordinated Management of Meaning as a framework proved to be of enormous benefit in being able to structure the write-up and make recommendations for future practice.

Since finishing the review, I am able to notice feelings of apprehension as it goes forward to publication. It makes me reflect on the number of research articles that make recommendations for future clinical practice that never get implemented by services and I notice a strange sense of guilt that I wish to continue my career working with children and young people when learning disabilities still seems to be an area that requires great change. This has led me to feel quite passionately about disseminating the review and I hope to look into the possibility of presenting the findings after it has been accepted for publication.

## **Case Studies**

Reflecting on the process of completing case studies over the past three years, it has made me more aware of how clinical psychologists can conduct research in busy clinical roles. Writing case studies has meant I have had to really examine and consider the evidence-base for my assessments, formulations and treatments and I think this has made me a better research and a better clinician. I have also had to consider the unique aspects of my work in more detail and what, in fact, does not fit with the evidence base. This has helped me to become more creative in my work and learn that people do not actually fit in to neat therapeutic ‘boxes’. They have also been really helpful in encouraging me to monitor outcomes and use these to inform the therapeutic intervention and address issues in the therapeutic alliance. It has also been really interesting and sometimes challenging to use outcome measure in services where this was not regularly completed as a routine part of assessment. Completing the case studies have also helped me gain a real respect for this type of research and its clinical relevance. I have noticed



when I have had to conduct a piece of clinical work and gone to the evidence base, sometimes I have found published case studies to be the most helpful forms of evidence to inform my work. I have found the way case studies document their interventions in detail and consider unique aspects invaluable in informing my practice. Due to this, I wish to continue completing and publishing case studies in my qualified practice.

## **Acknowledgements**

I would like to thank all of my project supervisors for their support in the development and execution of my projects. I would also like to thank my placement supervisors from whom I have learnt about what kind of clinical psychologist I wish to be.

I will always be grateful to the professionals who replied to my many letters and gave an eager psychology student a chance to volunteer in their services. I wouldn't have made this progress in my career without their belief in me and the early opportunities they gave me.

I would like to thank my family for their never-ending support and non-wavering belief that I would achieve my ambitions. I can't wait to continue to make you proud.

Thank you to my husband-to-be Sam. You never questioned moving to Bath with only a month's notice to be with me and I couldn't have done the last three years without your love and support.

Finally, I will always be eternally grateful to my amazing cohort. Very rarely have I been able to sit in a room full of people and be completely comfortable and myself, but you have all made that so easy. From the infamous reflective-practise session to Christmas clothing traditions, I don't think I will ever meet such a great group of people again in my life ('not me'). I want to thank you from the bottom of my heart and I know I have made friends for life. We got this.

Dedicated to my grandad, Owen Whittle.

## **Appendices**

### **Appendix A. Instructions for authors for literature review**

#### **RESEARCH IN DEVELOPMENTAL DISABILITIES**

##### **DESCRIPTION**

.Research In Developmental Disabilities is an international journal aimed at publishing original research of an interdisciplinary nature that has a direct bearing on the understanding or remediation of problems associated with developmental disabilities. Articles will be primarily empirical studies, although an occasional position paper or review will be accepted. The aim of the journal will be to publish articles on all aspects of developmental difficulties using rigorous research methods. Our aim is to publish the best available and most current research possible.

##### **GUIDE FOR AUTHORS**

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop.

Submissions will first be checked against the Aims and Scope and Guide for Authors by the Editor-in-Chief. If they are found to be suitable, they will be assigned to an Associate Editor who will assess the paper. If a paper meets the journal's criteria for scope, appropriateness and scientific rigour, a minimum of two independent reviewers will submit their comments to the Editor handling the paper, who will make a decision based upon the reviewers' comments. All accepted papers will therefore have received comments from a minimum of two independent reviewers and be reviewed by one or more editors.

##### **Peer review**

This journal operates a single blind review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of two independent expert reviewers to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. More information on types of peer review.

##### **Article structure**

##### **Article formatting and style**

Formatting and style in the text should follow the style used by the American Psychological Association. Font, headings, and other requirements stipulated should be adhered to.

##### **Word Count**

The maximum word count for articles submitted to the journal is 8,000 words, including references and tables.

##### **Subdivision - numbered sections**

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the

text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

#### Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

#### Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

#### Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

#### Results

Results should be clear and concise.

#### Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

#### Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

#### Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

#### Essential title page information

- Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower- case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
- Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.
- Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

#### Abstract

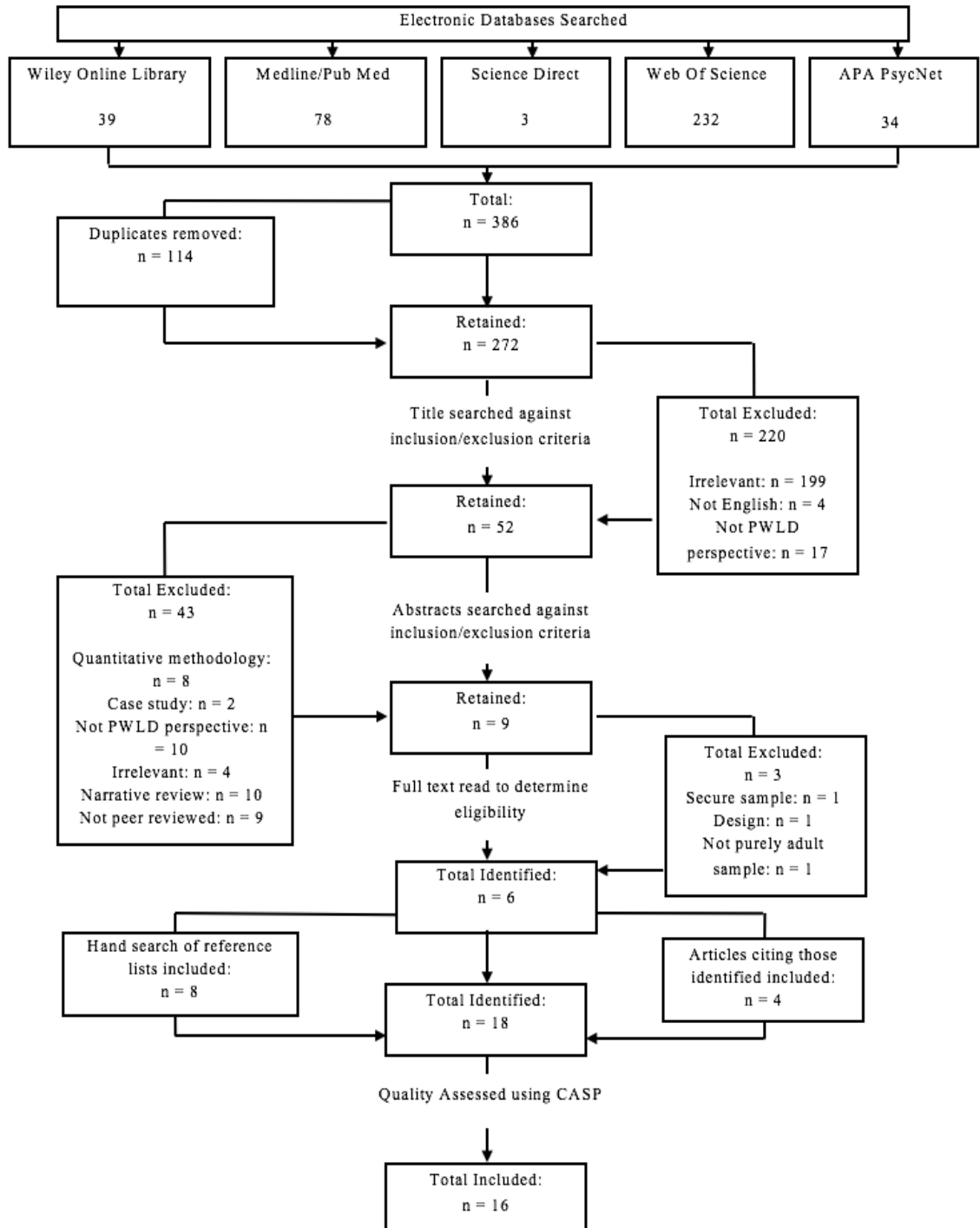
A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

#### Structured abstract

Authors should structure their abstract with the following sections: Background, Aims, Methods and Procedures, Outcomes and Results/Conclusions and Implications

The abstract should be no more than 200 words.

## Appendix B. Systematic Search



### Appendix C: Summary information of the papers included in the meta-ethnography

Reference	Title	Country	Sample	Data Collection	Analysis	Aim	CASP qualitative checklist Score
Study 1 Bernert (2011)	Sexuality and Disability in the Lives of Women with Intellectual Disabilities	USA	14 women	Ethnographic, in-depth interviews, formal observation and focus groups.	Grounded Theory	Explore how intellectual disability influences the way in which women experience their sexuality	12
Study 2 Azzopardi-Lane and Callus (2015)	Constructing sexual identities: people with intellectual disability talking about sexuality	Malta	19 men and women	Inclusive, focus groups.	Thematic analysis	To report on the social construction of sexuality of people with learning disabilities	16
Study 3 Healy, McGuire, Evans, and Carley (2009)	Sexuality and personal relationships for people with an intellectual disability. Part 1: Service-user Perspectives	Ireland	32 men and women	Focus group	Not stated	To gather information from people with learning disabilities about their knowledge, experiences and attitudes towards sexuality	15
Study 4 Sullivan, Bowden, McKenzie, and Quayle (2013)	“Touching people in relationships”: a qualitative study of close relationships for people with an intellectual disability	Scotland	10 men and women	Semi-structured Interviews	Interpretive phenomenological analysis	To explore the experiences and perceptions of close relationships in people with learning disabilities	20

Reference	Title	Country	Sample	Data Collection	Analysis	Aim	CASP qualitative checklist Score
Study 5 Yau, Ng, Lau, Chan, and Chan (2009)	Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context	Hong Kong	12 men and women	Semi-structured interviews	Inductive analysis	To examine the issues of sexual activity, marriage and parenthood and how people with learning disabilities learn about their own sexuality.	17
Study 6 Löfgren-Mårtenson (2004)	“May I?” About sexuality and love in the new generation with intellectual disabilities	Sweden	13 young adults	Ethnographic Observations and interviews	Dramaturgical perspective	To identify, describe and understand a new generation’s possibilities and hindrances for sexuality and love in view of the changes in society.	7*
Study 7 Bane et al. (2012)	Relationships of people with learning disabilities in Ireland	Ireland	97 men and women	Focus groups. Included people with LD as researchers.	Not Stated.	To identify what people with learning disabilities in Ireland thought about friendships and relationships.	18
Study 8 Bernert and Ogletree (2013)	Women with intellectual disabilities talk about their perceptions of sex	USA	14 women	Ethnographic Formal and informal observation and in-depth, semi-structured interviews	Not stated.	To explore sexuality in the lives of women with intellectual disability	16
Study 9	‘I don’t know what a proper woman means’: What	UK	10 women	Semi-structured interview	Thematic Analysis	To investigate the sexuality and sexual	19



Reference	Title	Country	Sample	Data Collection	Analysis	Aim	CASP qualitative checklist Score
Fitzgerald and Withers (2013)	women with intellectual disabilities think about sex, sexuality and themselves					identity of women with intellectual disabilities.	
Study 10 Kelly, Crowley, and Hamilton (2009)	Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'.	Ireland	15 men and women	Focus Group	Thematic Analysis	To provide an understanding of Irish people with learning disabilities' views, experiences and aspirations of sexuality and romantic relationships and to examine assistance they would like.	17
Study 11 Hollomotz (2009)	'May we please have sex tonight?' – People with learning difficulties pursuing privacy in residential group settings.	UK	15 men and women	Focus Group	Not stated	To examine privacy and sexual relationships of people with learning disabilities.	7*
Study 12 Lesseliers and Van Hove (2002)	Barriers to the development of intimate relationships and the expression of sexuality among	Belgium	34 men and women	In-depth, semi-structured interviews	Not stated but described	To understand how people with learning disabilities experience and interpret their environment and feelings in the context of their	18

Reference	Title	Country	Sample	Data Collection	Analysis	Aim	CASP qualitative checklist Score
Study 13 Turner and Crane (2016)	people with developmental disabilities: Their perceptions. Pleasure is paramount: Adults with intellectual disabilities discuss sensuality and intimacy.	USA	5 men and women	Semi-structured interviews and observations	Thematic Analysis	relational and sexual lives.  To examine how adults with learning disabilities describe their subjective experience and expression of romantic, and/or sexual relationships	19
Study 14 White and Barnitt (2000)	Empowered or discouraged? A study of people with learning disabilities and their experience of engaging in intimate relationships	UK	8 men and women	Semi-structured interviews	Qualitative methodology emerged from hermeneutic phenomenology	To examine whether people with learning disabilities feel empowered or discouraged when engaging in intimate relationships	16
Study 15 Lafferty, McConkey, and Taggart (2013)	Beyond Friendship: the nature and meaning of close personal relationships as perceived by people with learning disabilities	Ireland	16 heterosexual couples (8 men and 8 women)	Semi-structured interviews	Grounded Theory	To uncover the experiences of couples in a close personal relationship, the nature of these relationships and the meaning they ascribe to them.	17

Reference	Title	Country	Sample	Data Collection	Analysis	Aim	CASP qualitative checklist Score
Study 16 Neuman and Reiter (2016)	Couple relationships as perceived by people with intellectual disability – implications for quality of life and self-concept	Israel	20 heterosexual couples (10 men and 10 women)	Observations and semi-structured interviews	Thematic content analysis	To uncover how intimate relationships are perceived by people with intellectual disability.	14
Study 17 Rojas, Haya, and Lázaro-Visa (2014)	‘My great hope in life is to have a house, a family and a daughter’: Relationships and sexuality in intellectually disabled people	Spain	16 men and women (10 men, 6 women)	Semi-Structured interviews and images	Thematic coding process	To answer questions about sexuality in the lives of people with intellectual disability.	15
Study 18 (Rushbrooke, Murray, & Townsend, 2014)	The experiences of intimate relationships by people with intellectual disabilities: A qualitative study		9 (5 women, 4 men)	Semi-structured interviews	Interpretive Phenomenological Analysis	To contribute and expand the current evidence base for sexuality and intimate relationships for people with learning disabilities to bridge the gap between policy and practice.	19

**Appendix D: Included and excluded (\*) articles according to CASP qualitative checklist.**

Study Number	1	2	3	4	5	6*	7	8	9	10	11*	12	13	14	15	16	17	18
1. Clear statement of aims	2	1	2	2	2	1	2	2	2	2	0	2	2	2	2	2	1	2
2. Qualitative methodology appropriate	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3. Appropriate research design	1	2	2	2	2	0	2	2	2	1	0	2	2	2	2	2	2	2
4. Appropriate recruitment strategy	1	2	2	2	2	0	1	2	2	2	0	2	2	1	2	1	2	2
5. Consideration of data collection	1	2	2	2	2	0	2	2	2	2	1	1	2	2	2	1	2	2
6. Consideration of research relationships	0	1	0	2	1	2	2	0	2	1	0	2	1	0	0	0	0	2
7. Ethical issues considered	0	2	2	2	2	0	2	2	2	2	2	2	2	2	2	2	2	2
8. Rigorous data analysis	1	1	0	2	1	1	1	1	2	1	0	1	2	1	1	1	2	2
9. Findings clearly stated	2	2	2	2	2	1	2	2	2	2	1	2	2	2	2	1	1	2
10. Value of the research	2	1	1	2	1	0	2	1	1	2	1	2	2	2	2	2	1	1
<b>Total Score</b>	<b>12</b>	<b>16</b>	<b>15</b>	<b>20</b>	<b>17</b>	<b>7</b>	<b>18</b>	<b>16</b>	<b>19</b>	<b>17</b>	<b>7</b>	<b>18</b>	<b>19</b>	<b>16</b>	<b>17</b>	<b>14</b>	<b>15</b>	<b>19</b>

### Appendix E: Third order constructs and synthesized translations.

3 <sup>rd</sup> order constructs	Paraphrasing of second order constructs	Summary definition (translation) of the second order construct	Papers that include the 2 <sup>nd</sup> order construct
Cultural Beliefs of PWLD: Sociocultural Norms	Gender Roles	Gender stereotyped ideas about men and women in relationships according to gender roles expected within social norms.	5, 7, 9
	Traditional views on Marriage	Conventional and stereotyped view that sex only occurs within a monogamous marriage and only for the purpose of procreation.	3, 4, 5, 7, 8, 12, 13, 14, 15, 16, 17, 18
	Desire for relationships	A strong desire to be involved in an intimate relationship.	3, 5, 7, 10, 12, 13, 15, 17, 18
	Positive view of relationships	Being in a relationship associated with feeling happier, more confident and increased independence.	3, 4, 10, 12, 14, 15, 16, 18
	Choosing a partner	Searching for desired characteristics in a partner.	5, 10, 13, 14, 18
	No atypical relationships	No consideration of anything other than a heterosexual identify.	5, 8, 9
Relationships: Under Others Power	Inequality	Perception that maintaining and establishing relationships is easier for non-disabled people.	3, 9, 10, 17, 18
	Prohibition	Agencies prohibited expressions of sexuality ranging from displays of affection to intercourse.	1, 3, 9, 10, 12, 13, 18
	Involuntary Separation	Fear of losing a valued person or relationship due to one person in the relationship being moved to another supported home.	9, 10, 12, 16, 17
	External Power	The external management of relationships by staff and families	3, 4, 5, 9, 10, 12, 14, 16, 17, 18
	Restrictions	Excessive rules and restrictions related to sexual behaviours and relationships.	3, 4, 5, 10, 12, 14, 17, 18
	Adolescent relationships	Language and descriptions akin to adolescent relationships.	4, 5, 7, 9
	Sexual education	Incomplete or inaccurate knowledge of relationships, sex, bodily organs and function.	3, 5, 8, 9, 10, 12, 13, 14, 17
	Acquire knowledge about sex	Knowledge of sex acquired by through random and opportunistic ways.	5, 10, 12, 13, 18

3 <sup>rd</sup> order constructs	Paraphrasing of second order constructs	Summary definition (translation) of the second order construct	Papers that include the 2 <sup>nd</sup> order construct
Identity: Sexual Identity	Fearful consequences	Only associated sex with sickness and disease and negative consequences.	3, 5, 8, 9, 12, 18
	Support	Desired to be supported to maintain and establish relationships, express sexual needs and manage relationship conflicts.	2, 9, 10, 12, 14, 15, 18
	Isolation and Loneliness	Professionals thought it is adequate to provide activities for PWLD to combat loneliness but failed to facilitate relationships beyond friendship.	13, 15
	Assistance	Lives revolved around reliance on assistance to provide practical support to assist adaptive behaviours.	1, 4, 7, 13, 15, 18
	Sexual pride/sexual self-identity	Positive view of sexuality and their erotic potential to be sexual.	8, 12, 13, 18
	Distance self from sexuality	Ambivalence and denial towards own sexuality, anxiously defending against, hiding or suppressing the possibility of sexual relationships.	4, 5, 7, 9, 12, 13, 18
	Adult identity and Autonomy	Identified as being an adult, aware they have rights and believed they should have choices.	1, 2, 3, 15
	Internal conflict	Internal battle between the sexual norms prescribed to PWLD by the external world and their own internal sexual feelings and desires.	2, 4, 9, 13
	Rejection of Disability-Identity	Did not identify as having a learning disability and identified themselves as 'normal'.	1, 5, 9
	Sexuality of middle field	Kissing, cuddling, hugging, hand holding etc. but not sexual intercourse.	4, 12, 13, 16, 18
Episode: Sexual Experience	Communication between partners	Communication with partner about their sex life created basis where they could carefully explore and respect each other's boundaries.	12, 13
	Masturbation	Some did not know what masturbation was but others saw it as the only outlet to fulfil their sexual desires.	3, 5, 12, 13
	No pleasure	Rare or no pleasure language used by PWLD.	4, 8, 9, 12
	Negative Sexual Experiences	Some PWLD had past experiences of sexual abuse and exploitation which strongly influenced views and engagement in intimate relationships.	5, 8, 12, 14, 15, 16, 18

3 <sup>rd</sup> order constructs	Paraphrasing of second order constructs	Summary definition (translation) of the second order construct	Papers that include the 2 <sup>nd</sup> order construct
	Protective Sexual Strategies	Engaged in self-imposed abstinence, avoidance or secret sexual behaviours to avoid perceived negative consequences and reactions by others.	1, 3, 5, 8, 10, 12, 18

## **Appendix F: Instructions for authors**

### **Article types**

**Clinical Child Psychology and Psychiatry** is interested in advancing theory, practice and clinical research in the realm of child and adolescent psychology and psychiatry and related disciplines. Articles should not usually exceed 7,500 words and be clearly organized, with a clear hierarchy of headings and subheadings (3 weights maximum). Authors wishing to submit an article longer than 7,500 words should discuss this in advance with the journal editor.

### **Editorial Policies**

#### **Peer review policy**

The Editor will screen manuscripts for their overall fit with the aims and scope of the journal, especially in terms of having clear relevance for clinicians. Those that fit will be further reviewed by two or more independent reviewers in terms of merit, readability and interest. As part of the submission process you will be asked to provide the names of X peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

### **Authorship**

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

### **Publishing Policies**

#### **Publication Ethics**

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the [SAGE Author Gateway](#)

### **Plagiarism**

*Clinical Child Psychology and Psychiatry* and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or



relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

### **Reference Style**

Clinical Child Psychology and Psychiatry adheres to the APA reference style.

### **Manuscript Preparation**

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

### **Corresponding Author Contact details**

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

### **Guidelines for submitting artwork, figures and other graphics**

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

Figures, tables, etc.: should be numbered consecutively, carry descriptive captions and be clearly cited in the text. Keep them separate from the text itself, but indicate an approximate location on the relevant text page. Line diagrams should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

### **Ethical considerations**

The following ethical considerations apply to research articles, including case studies.



**Consent and confidentiality.** Disclosure should be kept to a minimum necessary to fulfil the objective of the article. All identifying details should be omitted. For both qualitative and quantitative studies, client or participant consent to participate should be obtained in accordance with ethics committee or institutional approval, and the study information sheets should include advice that the study findings may be published, and that no publications will reveal the identity of individual participants. For case studies, it is essential that the client provides written consent for their case to be published without them being identified, prior to a manuscript being submitted to Clinical Child Psychology and Psychiatry, with a statement to this effect being included in the manuscript text. Any material that is particularly distinctive should be omitted or aggregated. In case reports where ensuring anonymity is impossible, written consent must be obtained from the clients described, or their legal representative, and submitted with the manuscript.

**Ethics committee or institutional approval.** The manuscript must include a statement that confirms that the study is approved by the relevant human ethics research committee, or has institutional approval. Alternatively, for case studies the manuscript must include a statement confirming the client has provided written consent for their case to be published.


### Appendix G: Demographic information relating to participants

Participant Pseudonym	Gender	Age	Experience of Skype
Amanda	Female	< 16	Attending
Emily	Female	< 10	Attended, but since declined
Lily	Female	> 16	Declined
Anna	Female	< 16	Attending
Jacob	Male	< 16	Attending
Samantha	Female	< 16	Attending
Tom	Male	> 16	Declined
Rachel	Female	< 16	Attending

## Appendix H: Participant information sheet

 UNIVERSITY OF BATH Participant Information Sheet	 UNIVERSITY OF BATH Participant Information Sheet
<b>Research Invitation</b> <p>We are inviting young people (aged 18 and under) to take part in a research project about their experience of using (or not using) Skype within the Paediatric CFS/ME Service. Please read the information below and decide if you want to take part. This research is being run by Charlotte Whittle, Maria Loades and Sian McKenzie.</p>	<b>Benefits And Risks</b> <p>We cannot promise the study will help you directly but the information collected from you and other young people may help to improve our understanding of using Skype in clinical practice. However, we do hope to be able to improve the service young people receive by Skype after hearing about their experiences.</p> <p>Although we don't anticipate there to be any serious risks from taking part, we do appreciate that you may be inconvenienced in attending a discussion about your use of Skype appointments. Therefore we have tried to arrange the discussions so that they cause you the least disruption, by giving you the option of attending these by Skype, telephone or in person.</p>
<b>What we are researching</b> <p>The Paediatric CFS/ME Service has begun offering a number of appointments by Skype. We are interested in your experiences of using or not using Skype appointments so we can think about whether we need to make any improvements to our service.</p>	<b>Do I have to take part?</b> <p>No. It is your choice whether you take part and it will not affect the service you receive if you decide not to. If you decide to take part and then change your mind that is fine. You can withdraw at any time and ask for the information already gathered to be destroyed.</p> <p>What we find out from the study will be put into a report. Your name or any other information that might identify you will be anonymised and kept confidential, except in the circumstances where information is provided that may place the participant or others at risk.</p> <p>Although we don't anticipate there to be any serious risks from taking part, we do appreciate that you may be inconvenienced in attending a discussion about your use of Skype appointments. Therefore we have tried to arrange the discussions so that they cause you the least disruption, by giving you the option of attending these by Skype, telephone or in person.</p>
<b>What will happen if I take part?</b> <p>If you decide you would like to take part, the researcher Charlotte Whittle (a Clinical Psychologist in Training from The University of Bath) will contact you to ask how you would like to discuss your experiences or thoughts about Skype. You can decide whether you would like to talk to her by phone, in person (either at home or at the CFS/ME clinic in Bath) or over Skype and she will arrange a time and date with you. This conversation will last approximately 20-30 minutes and Charlotte will have a number of questions to ask you, but she is really keen to hear your own opinions.</p> <p><i>For example, the researcher might ask you to tell them a bit about your experiences of using Skype.</i></p> <p>All interviews will be recorded using a tape recorder so that the researcher can remember what you have said and record it accurately. These recordings will be securely locked away and will be destroyed once they have been written-up. If you do not want to be recorded but still wish to take part please talk to the researcher.</p> <p>Once we have collected a number of young people's perspectives on the use of Skype, we will write up everyone's experiences and thoughts and discuss with the Paediatric Chronic Fatigue Team whether there is any way we can improve the use of Skype within the service. Additionally, we may look to publish the thoughts of the young people in an academic journal, so other Paediatric Chronic Fatigue teams can think about how to best use Skype appointments in their own service.</p>	<b>How to take part</b> <p>If you would like to take part please let your clinician know.</p> <p>They will give you a contact form to fill in so Charlotte will know how best to contact you to talk a little bit about the project and ask for your consent to participate.</p> <p>Or to contact Charlotte directly you can email her at <a href="mailto:cw830@bath.ac.uk">cw830@bath.ac.uk</a>.</p>

## Appendix I: Consent to contact

 <b>UNIVERSITY OF BATH</b>	Consent to Contact Form
---	-------------------------

I have read the participant information sheet and give my permission for Charlotte Whittle to contact me.

Please tick the box if you agree ☐

**My preferred Contact Details**

Name \_\_\_\_\_

I would like to be contacted by:

(Please tick at least one)

Telephone	<input style="width: 40px; height: 20px; border: 1px solid black;" type="checkbox"/>
Email	<input style="width: 40px; height: 20px; border: 1px solid black;" type="checkbox"/>
Skype	<input style="width: 40px; height: 20px; border: 1px solid black;" type="checkbox"/>
Post	<input style="width: 40px; height: 20px; border: 1px solid black;" type="checkbox"/>

Telephone Number \_\_\_\_\_

Skype ID \_\_\_\_\_

Email Address \_\_\_\_\_

Home Address \_\_\_\_\_

\_\_\_\_\_

What days are best to contact you? (Please circle at least one)

**Monday      Tuesday      Wednesday      Thursday      Friday**

What times are best to contact you? (Please circle at least one)

**Morning (9am-12am)      Afternoon (12am-5pm)      Evening (5pm-8pm)**

**Thank you for taking the time to fill in this information**

Please give this form back to your clinician or post it back (please ask your clinician for a stamped address envelope).

Alternatively please scan it and/or send an email with your contact information to [cw830@bath.ac.uk](mailto:cw830@bath.ac.uk).

The information you have provided will not be used for any other purposes than to contact you for this research.

You have the right to withdraw your interest in this research at any point.

## Appendix J: Consent form for under 16s



Consent Form Under 16

### **Consent Form**

Young People's Experiences of Skype Appointments in a Paediatric Chronic Fatigue Service

The researcher for this project is Charlotte Whittle, a Clinical Psychologist in Training. She is based in the NHS and also registered with The University of Bath, undertaking a Doctorate in Clinical Psychology. Her work in this study is being conducted under the supervision of Maria Loades (University of Bath) and Jennifer Collins (CFS/ME Service). These will be the only other people who will have access to the information collected in this study. Participants will not be able to be identified from the information.

#### **The researcher will have explained the following to you and the young person:**

1. What we are researching and why the young person has been asked to take part
2. What will happen if the young person decides to take part
3. The possible benefits and risks of taking part
4. That the interview is to be audio recorded and the reasons for this.
5. That the information that the young person provides will be made anonymous and kept confidential, except in the circumstances where information is provided that may place the young person or others at risk.
6. That the young person has the right to withdraw from the study at any point and can request for any information that has already been provided to be withdrawn from the study and destroyed.
7. Participation or not in the study will not affect the service the young person receives.
8. The final write-up of this study (with all findings anonymised) may be published in an academic journal and presented at meetings or conferences.

**By signing below you agree you have understood the above 8 points and agree to the young person participating in the study.**

\_\_\_\_\_  
Name of parent/guardian (Print)      Signature of parent/guardian      Date

\_\_\_\_\_  
Name of researcher (Print)      Signature of researcher      Date

**For The Young Person:** I agree to take part in this study.

\_\_\_\_\_  
Name of participant (Print)      Signature of participant      Date

## Appendix K: Consent form for 16 and over



Consent Form 16+

### **Consent Form**

Young People's Experiences of Skype Appointments in a Paediatric Chronic Fatigue Service

The researcher for this project is Charlotte Whittle, a Clinical Psychologist in Training. She is based in the NHS and also registered with The University of Bath, undertaking a Doctorate in Clinical Psychology. Her work in this study is being conducted under the supervision of Maria Loades (University of Bath) and Jennifer Collins (CFS/ME Service). These will be the only other people who will have access to the information collected in this study. Participants will not be able to be identified from this information.

#### **The researcher will have explained the following to you:**

1. What we are researching and why you have been asked to take part
2. What will happen if you take part
3. The possible benefits and risks of taking part
4. That the interview is to be audio recorded and the reasons for this.
5. That the information that you provide will be made anonymous and kept confidential, except in the circumstances where information is provided that may place the participant or others at risk.
6. That you have the right to withdraw from the study at any point you wish and that you request for any information that you have provided to be withdrawn from the study and destroyed.
7. Participation or not in the study will not affect the service you receive.
8. The final write-up of this study (with all findings anonymised) may be published in an academic journal and presented at meetings or conferences.

**By signing below you agree that you have understood the above 8 points and agree to participate in the study.**

\_\_\_\_\_  
Name of participant (Print)      Signature of participant      Date

\_\_\_\_\_  
Name of researcher (Print)      Signature of researcher      Date

**For Parents/Guardians.** I agree for the above young person to take part in this study.

\_\_\_\_\_  
Name of parent/guardian (Print)      Signature of parent/guardian      Date

## **Appendix L: Semi-structured interview schedule**

**Initial Question:** How many times have you used Skype to attend appointments in the Paediatric Chronic Fatigue Service?

- **If participants currently use Skype to attend appointments follow interview schedule 1**
- **If participants have declined to use Skype to attend appointments follow interview schedule 2**
- **If participants have used Skype to attend appointments and since declined follow interview schedule 3**

### Interview Schedule 1: Uses Skype to attend appointments

**Question: What made you decide to use Skype for appointments?**

Prompts:

- Expectations?
- Staff influences?
- Concerns?
- Why Skype rather than telephone or face to face?
- Location?

**Question: Tell me a bit about your experience of using Skype?**

Prompts:

- Positives experiences?
- Negative experiences?
- Any difficulties?
- Imagined difficulties of using Skype?
- Best things?
- Worst things?

**Question: Why do you think some young people don't want to use Skype?**

Prompts:

- Negative experiences?
- Would other young people agree with you?

**Question: Do you have any thoughts or suggestions about how Skype appointments could be better?**

**Question: Is there anything you would like to add to or expand on regarding skype appointments and what we have discussed today?**

Interview Schedule 2: Does Not Use Skype to Attend Appointments

**Question: What made you decide not to use Skype?**

Prompts:

- Expectations?
- Staff influence?
- Concerns?
- Why telephone or face to face over Skype?
- Location?

**Question: Tell me a bit about your experiences of using Skype in the past?**

Prompts:

- Positives experiences?
- Negative experiences?
- Any difficulties?
- Imagined difficulties of using Skype?
- Best things?
- Worst things?

**Question: Why do you think some young people want to use Skype?**

Prompts:

- Good experiences?
- What would influence their decision?
- Why don't you agree with them?

**Question: Do you have any thoughts or suggestions about how Skype appointments could be better?**

Prompts:

- Would that make you more likely to use Skype?

**Question: Is there anything you would like to add to or expand on regarding Skype appointments and what we have discussed today?**

Interview Schedule 3: Initial Used Skype to Attend Appointments, But Then Opted Out

**Question: Tell me a bit about your experiences of using Skype**

Prompts:

- Positives experiences?
- Negative experiences?
- Any difficulties?



- Imagined difficulties of using Skype?
- Best things?
- Worst things?

Question: **What do you think influenced your decision to stop using Skype?**

Prompts:

- Expectations?
- Staff influence?
- Concerns?
- Why telephone or face to face over Skype?
- Location?

Question: **Why do you think some young people continue to use Skype?**

Prompts:

- Good experiences?
- What would influence their decision?
- Do you not agree with them?

Question: **Do you have any thoughts or suggestions about how Skype appointments could be better?**

Prompts:

- Would you ever use Skype again?
- What would have to change to mean you were more likely to use Skype?

Question: **Is there anything you would like to add to or expand on regarding Skype appointments and what we have discussed today?**

Main Theme	Theme Summary	Subthemes
		Therapeutic engagement

‘A different connection’: Therapeutic experience and engagement	Face to face appointments are preferable but Skype is the next best thing, especially in place of no service. For some, Skype can create a barrier to personal connection with therapist, but for others Skype doesn’t affect session quality and in some cases improves it.	Therapeutic experience
‘It was a little chaotic, but it was ok’: Anticipations, preparations and technology use	Concerns and anticipatory anxieties about using Skype. Therefore, making preparations for the use of Skype helps to reduce fears of the unknown. Issues with technology a reality but mostly acceptance and accommodation of these issues present. Costs and benefits of sharing resources through technology.	Easing anticipations by preparing for Skype Using the technology Sharing resources
‘It was way easier to access’: Accessibility and the impact of CFS/ME symptoms	Skype allows young people who are significantly unwell or far away to access evidence-based therapies they would not otherwise be able to access. Skype can negatively and positively impact on CFS/ME symptoms. Skype can help young people feel more in control of their treatment and reduce the disruption attending treatment can have on young people’s lives, for instance their school attendance.	Improving access Mutual impact of CFS/ME symptoms In control of environment

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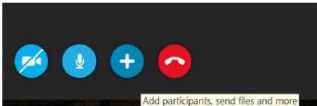
#### **Appendix M: Main Themes, Theme summaries and Subthemes**

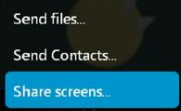
#### **Appendix N: Recommendations presented to the Specialist Paediatric CFS/ME Team.**

No.	Recommendation Details
1	Don't make assumptions about the young person's experiences, opinions or knowledge of Skype. Always ask them if they would like more information when first discussing the use of Skype. Create a leaflet that addresses issues of concern as outlined by the participants in this research; for example, confidentiality, location of therapist, step-by-step guide on how to set up Skype and how to use it, and website information for downloading activity diaries and information leaflets.
2	Ensure that commonly used leaflets and diaries are made downloadable from the website
3	Prioritise the use of Skype for young people who are significantly impacted by their symptoms, or live an excessive distance from the clinic.
4	Provide trouble shooting to overcome any technical issues. For example, make sure young people know how to disconnect and reconnect to Skype and make necessary arrangements to offer a phone call as a contingency option.
5	Explore the possibility of including and introducing screen-sharing technology as an adjunct to Skype to aid the exchange of information and learning between the therapist and young person.
6	Explore the possibility of using different programmes to suit the young people in addition to Skype, for example Facetime and Discord.
7	Consider investing in a higher quality and clearer webcam and microphone.
8	Be aware of the placement of the webcam during sessions to account for the reduced eye contact during Skype sessions.
9	Consider the timings of Skype appointments, either at the beginning or end of the day to reduce the impact on young people of having to leave school to attend appointments.
10	Be mindful of any CFS/ME symptoms that might affect the young person's ability to engage with sessions over Skype, for example increased visual strain from looking at a screen.
11	Give young people the option to meet with their clinician face to face before starting Skype appointments; if this is not a possibility offer them a phone call first as a minimum.

## Appendix O: Information leaflet for CYP and families.

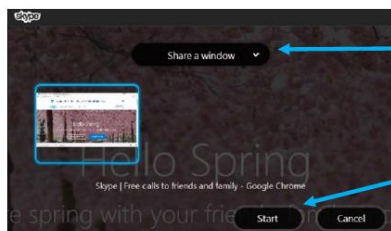
### Screen sharing

To share your whole screen, or just a single document with your therapist, while you're in a Skype call, press the blue + sign along the bottom of the video, and select 'Share screens...'.  




If you want to share your whole screen, click 'Start' along the bottom.

If you want to share just a single document, click on the dropdown menu that says 'Share your screen' and select 'Share a window', click on the picture of the document you want to share, and then click 'Start' along the bottom. (Please note: you need to have the document open on your computer already).

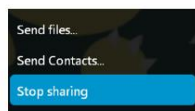


Dropdown menu

Start

If your therapist wants to share their screen or a document with you, they will follow the above steps and their screen/document will just appear on your screen without you needing to do anything.

To stop sharing your screen/window, just click back on the blue + sign in the main Skype window, and click 'Stop sharing', or click 'Stop sharing' at the bottom of the little Skype window which will be open if you do not have the main Skype window open.



Thank you for reading! You can download activity diaries and information leaflets directly from the CFS/ME website which can be found here: [http://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/index.asp?menu\\_id=1](http://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/index.asp?menu_id=1)



Royal United Hospital Bath **NHS**  
NHS Trust

### Using Skype with the Paediatric CFS/ME Service



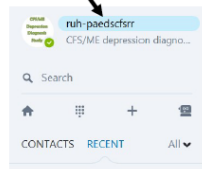
A guide to attending sessions with your  
clinician over Skype

## Sharing Skype details

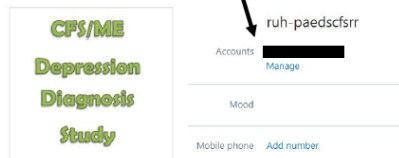
### How do I get in contact with the clinician?

Your clinician will need a way to contact you. Click on your name in the top left corner of the Skype screen, then provide the clinician with the username, phone number, or email address written next to "Accounts".

#### 1. Click here



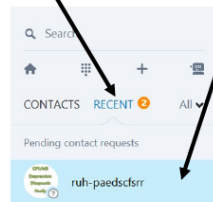
#### 2. Share this with your clinician



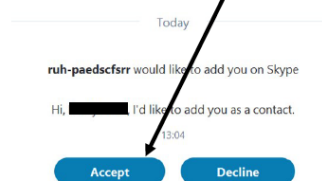
Make sure that before your appointment, you have opened the Skype app and logged in.

Your clinician might add you as a contact before calling you. Click on 'Recent' to check for new contact requests, then click on the clinician's name, and 'Accept' to add them as a contact.

#### 3. Click here



#### 4. Click here



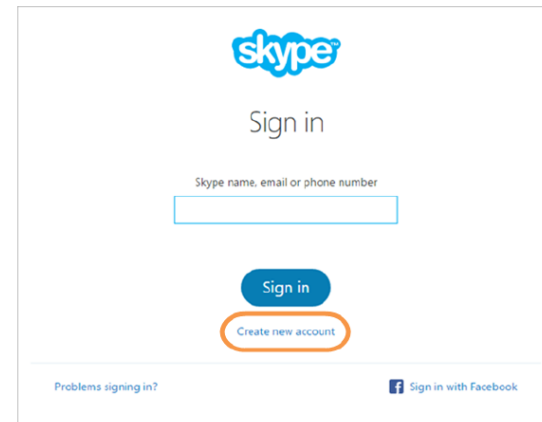
#### 5. Click here

Alternatively, the clinician might call you on Skype without adding you as a contact.

## Setting up Skype

### How do I set up Skype on my computer or device?

1. Visit the Skype website at <https://www.skype.com/en/>
2. Click on 'Download Skype'.
3. If you have a Windows computer, click on 'Get Skype for Windows'. If you have a Mac, click on 'Learn about Skype for Mac' and then 'Get Skype for Mac'.
4. Follow the onscreen steps to download Skype. Once it has finished installing, open Skype.
5. On the Skype sign in screen (below), select Create new account (or go directly to the Create an account page).

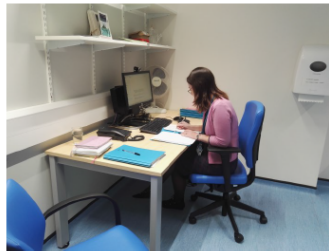


6. Follow the onscreen steps to set up a Skype account.

## Your confidentiality

### Where will the clinician be sitting during the Skype session?

Your clinician will be sat in a quiet, private room when meeting you over Skype. The room will be very similar set-up to clinic rooms where you may have had a face to face meeting with a member of the CFS/ME team before. No one else will be present in the room without your knowledge and no one else will be able to overhear your conversations by Skype.



### How confidential is video-calling over Skype?

All Skype-to-Skype voice, video, file transfers and instant messages are encrypted. This means that all conversations are confidential and protected from anyone being able to listen in.

For more information please follow this link:

<https://support.skype.com/en/faq/FA31/does-skype-use-encryption>

### How do I protect my online security when using Skype?

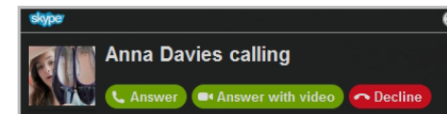
If you are worried about keeping your password or your computer safe please follow this link for more information about how to protect your online security when using Skype:

<https://support.skype.com/en/faq/FA34649/protecting-your-online-safety-security-and-privacy>

## Making Skype calls

### How do I call the clinician?

You do not need to video-call your clinician as they will always video-call you on Skype at the agreed time for the appointment. This means all you need to do is answer the call. When someone calls you, a call alert window appears on your screen:



Click...	To...
Answer	answer the call (voice only, no video)
Answer with video	answer the call with video
Decline	reject the call

### What do I do if I'm having technical issues with the Skype video-call?

If you are having technical issues with the Skype video-call, for example the sound or video keeps cutting out, try following this link to troubleshoot the problem:

<https://support.skype.com/en/faq/FA897/troubleshooting-problems-with-skype-calls>

If you can't resolve the technical issue during your video-call, your clinician should try ringing you on your telephone number to continue the day's session by telephone.

## **Appendix P: Instructions for authors**

### **Manuscript Types and Length**

Stigma and Health accepts both regular articles and brief reports.

Articles should not exceed 25 pages inclusive of the introduction, methods, results, and discussion. Tables, figures and references may be outside of this page limit. Authors may request consideration of longer papers, in advance of submission, when there is clear justification for additional length.

Brief reports should be a maximum 1,800 words (excluding abstract, references, and table/figure), plus no more than 15 references and one table or figure.

Manuscripts based in the following realms are also encouraged:

Qualitative studies

Survey research

Quantitative tests of hypotheses about the form and impact of stigma

Theoretical reviews and pioneering reports on innovations

Research studies on methods meant to erase the stigma of mental and physical illnesses

First person essays about experience with stigma

The journal will likewise consider lengthier theory-based papers with permission from the editor.

### **Masked Review**

This journal has adopted a policy of masked review for all submissions. The title page should include all authors' names and institutional affiliations and full contact information for the corresponding author. The first page of text should omit this information but should include the title of the manuscript and the date it is submitted. Every effort should be made to see that the manuscript itself contains no clues to the authors' identity.

### **Manuscript Preparation**

Prepare manuscripts according to the Publication Manual of the American Psychological Association, 6th Edition (2010). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the Publication Manual).

Review APA's Checklist for Manuscript Submission before submitting your article.

### **Formatting**

Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the Manual. Additional guidance on APA Style is available on the APA Style website.

### **Tables**

Use Word's Insert Table function when you create tables. Using spaces or tabs in your table will create problems when the table is typeset and may result in errors.

Submitting Supplemental Materials

APA can place supplemental materials online, available via the published article in the PsycARTICLES® database. Please see Supplementing Your Article With Online Material for more details.

### **Abstract and Keywords**

All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

## References

List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.

Examples of basic reference formats:

### Journal Article:

Hughes, G., Desantis, A., & Waszak, F. (2013). Mechanisms of intentional binding and sensory attenuation: The role of temporal prediction, temporal control, identity prediction, and motor prediction. *Psychological Bulletin*, 139, 133–151. <http://dx.doi.org/10.1037/a0028566>

### Authored Book:

Rogers, T. T., & McClelland, J. L. (2004). *Semantic cognition: A parallel distributed processing approach*. Cambridge, MA: MIT Press.

### Chapter in an Edited Book:

Gill, M. J., & Sypher, B. D. (2009). Workplace incivility and organizational trust. In P. Lutgen-Sandvik & B. D. Sypher (Eds.), *Destructive organizational communication: Processes, consequences, and constructive ways of organizing* (pp. 53–73). New York, NY: Taylor & Francis.

## Figures

Graphics files are welcome if supplied as Tiff or EPS files. Multipanel figures (i.e., figures with parts labeled a, b, c, d, etc.) should be assembled into one file.

The minimum line weight for line art is 0.5 point for optimal printing.

For more information about acceptable resolutions, fonts, sizing, and other figure issues, please see the general guidelines.

When possible, please place symbol legends below the figure instead of to the side.

APA offers authors the option to publish their figures online in color without the costs associated with print publication of color figures.

The same caption will appear on both the online (color) and print (black and white) versions. To ensure that the figure can be understood in both formats, authors should add alternative wording (e.g., "the red (dark gray) bars represent") as needed.





### **Research Invitation – Exploring Disclosure**

We are inviting adults over the age of 18 who have experienced a mental health problem to complete a few questionnaires about whether they have disclosed their experiences and to whom, their general well-being, expectations of disclosure and their experiences of social support and self-stigma.

Please read the information below and decide if you would like to take part.

This research is being run by Charlotte Whittle and Lorna Hogg in association with the University of Bath. If you would like to contact Charlotte Whittle directly to ask further questions, please email her using **[cw830@bath.ac.uk](mailto:cw830@bath.ac.uk)**

### **What we are researching**

We are interested in finding out whether adults who have experienced a mental health problem find disclosing their experiences stressful and whether this distress is associated with their decisions to disclosure, their well-being and their experiences of social support and self-stigma. We are also trialling a new questionnaire aimed at reporting on disclosure stress and results from this study will provide reliability and validity data so other researchers can use it in the future.

### **What will happen if I take part?**

If you decide you would like to take part, you will be asked to complete a consent form and then to complete a small series of questionnaires.

This will include six questionnaires covering the following topics:

<b>Demographic information</b>	<b>Level of disclosure</b>	<b>General well-being</b>
<b>Social support</b>	<b>Disclosure stress</b>	<b>Self-stigma</b>

These should take approximately 15-20 minutes to complete.

### **Potential Benefits And Risks**

Although we do not anticipate benefits to you directly, we hope that the information gathered from this research will help others in the future by learning about how people experience disclosure and planning appropriate support strategies.

Although we do not anticipate any risks arising from this research, we recognise that the topic of disclosure may be distressing to some. If you feel distressed by any of the topics raised in this research confidential support agency information will be provided to you.

### **Do I have to take part?**

**No.** It is entirely your choice whether you take part. If you decide to take part and then change your mind that is fine. You can withdraw at any time and ask for the information already gathered to be destroyed.

What we find out from the research will be put into a research article, any information that you provide will be anonymised and kept confidential.

## Appendix R: Online consent form

This part of the survey uses a table of questions, [view as separate questions instead?](#)

**Please indicate below if you have understood the information provided to you on the previous page. Please feel free to refer back to the information on the previous page if you need to.** If you have any questions please email [cw830@bath.ac.uk](mailto:cw830@bath.ac.uk) \* *Required*

	Yes	No
What we are researching and why you have been asked to take part	<input type="checkbox"/>	<input type="checkbox"/>
What will happen if you take part	<input type="checkbox"/>	<input type="checkbox"/>
The possible benefits and risks of taking part	<input type="checkbox"/>	<input type="checkbox"/>
That the information you provide will be made anonymous and kept confidential	<input type="checkbox"/>	<input type="checkbox"/>
That you have the right to skip any questions or withdraw from the research at any point you wish and that you can request for any information that you have provided to be withdrawn from the study and destroyed (up until the point of data analysis).	<input type="checkbox"/>	<input type="checkbox"/>
The final write-up of this study (with all findings anonymized) may be published in an academic journal and presented at meetings or conferences.	<input type="checkbox"/>	<input type="checkbox"/>

**I have ticked yes to the above 6 points and agree to participate in the research.** \* *Required*

- ☐ Yes  
☐ No

## Appendix S: Demographic Questionnaire

1. How old are you?

---

2. What is your gender?

Male

Female

Transgender

Other

Prefer not to say

3. How would you define your sexual orientation?

---

4. What is your ethnic group? (Please mark one)

**White**

\_\_\_ English/Welsh/Scottish/Northern Irish/British

\_\_\_ European/Other

**Mixed/Multiple Ethnic Groups**

\_\_\_ White and Black Caribbean

\_\_\_ White and Black African

\_\_\_ White and Asian

**Black/African/Caribbean/Black British**

\_\_\_ Caribbean

\_\_\_ African

**Asian**

\_\_\_ Indian

\_\_\_ Pakistani

\_\_\_ Bangladeshi

\_\_\_ Chinese

\_\_\_ **Any Other Ethnic Group**

Any Other (Please specify)\_\_\_\_\_

5. In what country are you currently living?

---

- 6. Do you identify yourself as having experienced a mental health problem?** Please indicate on the list below if you have experienced any of the following mental health problems. It does not matter if you have not received a formal diagnosis, or if you are currently experiencing these problems or have experienced them in the past. Please tick as many as you feel apply.

Schizophrenia/Psychosis  
Bipolar/Mania  
Depression  
Panic Disorder  
Agoraphobia  
Specific Phobia  
Generalized Anxiety Disorder  
Obsessive-Compulsive Disorder  
Hoarding  
Social Anxiety  
Post-Traumatic Stress Disorder  
Health Anxiety/Hypochondriasis  
A Dissociative Disorder (e.g. dissociative identify disorder)  
Anorexia Nervosa  
Bulimia Nervosa  
Other Eating Disorder  
Conduct Disorder  
Personality Disorder

Other: (please specify below)

- 7. If you have identified more than one mental health problem please indicate which one you think is the primary difficulty** E.g. the problem which was/is maintaining your other difficulties, or caused/is causing you the most distress, or impacted/impacts most upon your life.

---

- 8. Do you consider yourself to have a long-term physical health problem or disability?**

Yes                      No                      Prefer Not To Say

If yes, please specify below:

## Appendix T: Average number of disclosures and satisfaction measure

Below is a list of different areas of life. Please specify approximately how many people you have disclosed your mental health problems to in each area.

---

### 1. Immediate Family (e.g. mum, dad, siblings, step-siblings, grandparents etc)

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------	---------------------	----------------	------------	----------------	--------------------------	-----------------------------

#### How satisfied are you with that number of disclosure?

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
------------------	------------------	---------	----------------	------------

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### 2. Extended Family (e.g. cousins, aunties, uncles, etc)

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------	---------------------	----------------	------------	----------------	--------------------------	-----------------------------

#### How satisfied are you with that number of disclosure?

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
------------------	------------------	---------	----------------	------------

---

### 3. Friends

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------	---------------------	----------------	------------	----------------	--------------------------	-----------------------------

#### How satisfied are you with that number of disclosure?

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
------------------	------------------	---------	----------------	------------

---

#### 4. People at college/education facility

If you do not currently attend college or an education facility please move on to question 5.

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------------	------------------------	-------------------	---------------	-------------------	--------------------------------	-----------------------------------

**How satisfied are you with that number of disclosure?**

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
---------------------	---------------------	---------	-------------------	------------

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#### 5. People at work

If you do not currently attend work please move to question 6.

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------------	------------------------	-------------------	---------------	-------------------	--------------------------------	-----------------------------------

**How satisfied are you with that number of disclosure?**

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
---------------------	---------------------	---------	-------------------	------------

---

#### 6. Professionals (e.g. mental health clinicians, GP)

no one or almost no one	less than a quarter	less than half	About half	more than half	More than three quarters	Everyone or almost everyone
-------------------------------	------------------------	-------------------	---------------	-------------------	--------------------------------	-----------------------------------

**How satisfied are you with that number of disclosure?**

Not at all happy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
---------------------	---------------------	---------	-------------------	------------

## Appendix U: The Cognitive Appraisal of Disclosure as a Stressor Measure

We are interested in how you feel about the following statements.

Please read each statement carefully and indicate how you currently feel about each statement

**1. Disclosing my mental health problems to others will have a negative impact on my future.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**2. Disclosing my mental health problems will have harmful or bad consequences for me.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**3. Disclosing my mental health problems will negatively affect many areas of my life.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**4. Disclosing my mental health problems will have a severe impact on my life.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**5. I am prepared to deal with people's reactions to disclosing my mental health problems.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**6. I have the resources I need to handle problems posed by disclosing my mental health problems.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**7. I will do the best I can to cope with people's reactions to disclosing my mental health problems.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

**8. I am able to rise up and meet the demands posed by disclosing my mental health problems.**

0	1	2	3	4	5	6
Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Mostly Agree	Strongly Agree

## Appendix V: Multidimensional Scale of Perceived Social Support

We are interested in how you feel about the following statements.  
Read each statement carefully. Please Indicate how you feel about each statement by ticking the appropriate box.

### **There is a special person who is around when I am in need**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **There is a special person with whom I can share my joys and sorrows**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **My family really tries to help me**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **I get the emotional help and support I need from my family**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **I have a special person who is a real source of comfort to me**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **My friends really try to help me**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **I can count on my friends when things go wrong**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

### **I can talk about my problems with my family**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree



**I have friends with whom I can share my joys and sorrows**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

**There is a special person in my life who cares about my feelings**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

**My family is willing to help me make decisions**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

**I can talk about my problems with my friends**

1	2	3	4	5	6	7
Very strongly disagree	Strongly disagree	Mildly disagree	Neutral	Mildly agree	Strongly agree	Very strongly agree

## Appendix W: The Self-Stigma of Mental Illness Scale – Short Form

The public has believed many different things about persons with serious mental health problems over the years, including some things that could be considered offensive. We would like to know what you think most of the public as a whole, or most people in general, believe about persons with serious mental health problems at the present time. Please answer the following items using the 9-point scale below.

1	2	3	4	5	6	7	8	9
I Strongly Disagree	I disagree	I moderately disagree	I mildly disagree	I Neither Agree or Disagree	I mildly agree	I moderately agree	I agree	I Strongly Agree

### I think the public believes...

1. \_\_\_\_\_ most persons with mental health problems are to blame for their problems.
2. \_\_\_\_\_ most persons with mental health problems are unpredictable.
3. \_\_\_\_\_ most persons with mental health problems will not recover or get better.
4. \_\_\_\_\_ most persons with mental health problems are dangerous.
5. \_\_\_\_\_ most persons with mental health problems are unable to take care of themselves.

Now please answer the following items using the same scale.

1	2	3	4	5	6	7	8	9
I Strongly Disagree	I disagree	I moderately disagree	I mildly disagree	I Neither Agree or Disagree	I mildly agree	I moderately agree	I agree	I Strongly Agree

### I think...

1. \_\_\_\_\_ most persons with mental health problems are to blame for their problems.
2. \_\_\_\_\_ most persons with mental health problems are unpredictable.
3. \_\_\_\_\_ most persons with mental health problems will not recover or get better.
4. \_\_\_\_\_ most persons with mental health problems are dangerous.
5. \_\_\_\_\_ most persons with mental illness are unable to take care of themselves.

Now please answer the following items using the same scale.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>
I Strongly Disagree	I disagree	I moderately disagree	I mildly disagree	I Neither Agree or Disagree	I mildly agree	I moderately agree	I agree	I Strongly Agree

**Because I have a mental health problem...**

1. \_\_\_\_\_ I am unable to take care of myself.
2. \_\_\_\_\_ I will not recover or get better.
3. \_\_\_\_\_ I am to blame for my problems.
4. \_\_\_\_\_ I am unpredictable.
5. \_\_\_\_\_ I am dangerous.

Finally, please answer the following items using the same scale.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>
I Strongly Disagree	I disagree	I moderately disagree	I mildly disagree	I Neither Agree or Disagree	I mildly agree	I moderately agree	I agree	I Strongly Agree

**I currently respect myself less...**

1. \_\_\_\_\_ because I am unable to take care of myself.
2. \_\_\_\_\_ because I am dangerous.
3. \_\_\_\_\_ because I am to blame for my problems.
4. \_\_\_\_\_ because I will not recover or get better.
5. \_\_\_\_\_ because I am unpredictable.

## Appendix X: Warwick-Edinburgh Mental Wellbeing Scale

### Below are some statements about feelings and thoughts.

Please tick (✓) the box that best describes your experience of each over the **last 2 weeks**

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

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## Appendix Y: Debrief form

### Debrief Form

Thank you for taking part in this research.

Being able to talk to friends and other trusted people can be really beneficial to helping people cope with problems. However, previous research indicates that people who experience mental health difficulties may find it difficult to talk to others about their experiences for fear of being rejected and stigmatized. This means they may be missing out on valuable social support and internalizing the harm triggered by public stigma.

In this study, we were interested in finding out whether adults who have experienced mental health problems find disclosing their experiences stressful and whether this distress is associated with their decisions to disclose and their experiences of social support and self-stigma.

---

If you have found taking part in this research distressing or it has raised any issues you would like to discuss further, please contact the following confidential support services

For Samaritans call 116 123

For MIND call 0300 123 3393 or text 86463

For SANE call 0300 304 7000

Alternatively, if you are in touch with mental health services please seek support from your service by speaking to a clinician, or if you feel able to please talk to a family member, friend or your GP.

## Appendix Z: Information sheet



Participant Information Sheet – Part B

### **Research Invitation – Exploring Disclosure by Interview**

We are inviting adults over the age of 18 who have experienced a mental health problem to take part in an interview about their experiences of disclosing or not disclosing their mental health difficulties to others.

Please read the information below and decide if you would like to take part.

This research is being run by Charlotte Whittle and Lorna Hogg in association with the University of Bath. If you would like to contact Charlotte Whittle directly to ask further questions, please email her using **[cw830@bath.ac.uk](mailto:cw830@bath.ac.uk)**

#### **What we are researching**

We are interested in finding out a bit more about people's individual experiences of disclosing or concealing their experiences of mental health difficulties from others, what influences these decisions and what impact disclosure or concealment can have on people.

#### **What will happen if I take part?**

If you decide you would like to take part, the researcher Charlotte Whittle (a Clinical Psychologist in Training from The University of Bath) will contact you to ask how you would like to be interviewed; either by telephone, Skype or face to face (depending on your location) and arrange a date and time to do so. The interview will last approximately 30-40 minutes and you will be asked a number of questions. You are free to skip any questions or terminate the interview at any time.

*For example, the researcher might ask you to tell them about what influenced your experience of disclosure or concealment.*

All interviews will be recorded using a tape recorder so that the researcher can remember what has been said and can record it accurately. These recordings will be securely locked away and will be destroyed once they have been written-up.

#### **Potential Benefits and Risks**

Although we do not anticipate benefits to you directly, we hope that the information gathered from this research will help others in the future by learning about how people experience disclosure or concealment and planning appropriate support strategies.

Although we do not anticipate any risks arising from this research, we recognise that the topic of disclosure may be distressing to some. If you feel distressed by any of the topics raised in this research confidential support agency information will be provided to you.

#### **Do I have to take part?**

**No.** It is entirely your choice whether you take part. If you decide to take part and then change your mind that is fine. You can withdraw at any time and ask for the information already gathered to be destroyed.

What we find out from the research will be put into a research article, any information that you provide will be anonymised and kept confidential.

## Appendix AA: Consent form

This part of the survey uses a table of questions, [view as separate questions instead?](#)

Please indicate below if you have understood the information provided to you on the previous page. Please feel free to refer back to the information on the previous page if you need to. If you have any questions please email [cw830@bath.ac.uk](mailto:cw830@bath.ac.uk)

Please don't select more than 1 answer(s) per row.

Please select at least 1 answer(s).

	Yes	No
What we are researching and why you have been asked to take part	<input type="checkbox"/>	<input type="checkbox"/>
What will happen if you take part	<input type="checkbox"/>	<input type="checkbox"/>
The possible benefits and risks of taking part	<input type="checkbox"/>	<input type="checkbox"/>
That the information you provide will be made anonymous and kept confidential	<input type="checkbox"/>	<input type="checkbox"/>
That you have the right to skip any questions or withdraw from the research at any point you wish and that you can request for any information that you have provided to be withdrawn from the study and destroyed (up until the point of data analysis).	<input type="checkbox"/>	<input type="checkbox"/>
The final write-up of this study (with all findings anonymized) may be published in an academic journal and presented at meetings or conferences.	<input type="checkbox"/>	<input type="checkbox"/>
That the interview is to be audio recorded and the reasons for this.	<input type="checkbox"/>	<input type="checkbox"/>

### I have ticked yes to the above 7 points and agree to

**participate in the research.** You must have ticked yes to all 7 points to take part in the research, if you have ticked no to any item but wish to participate please feel free to go back and read the previous page where all the information is listed.

- ☐ Yes  
☐ No

< Previous

Next >

## **Appendix AB: Interview topic guide**

- **Where you say you stand on disclosing your mental health problems?**
- **Experiences of Disclosure**
  - Positive and negatives of this experiences
  - How has it or might it affect future disclosures
  - What has influenced your decision to disclose
  - Role of social media – costs and benefits
- **Experiences of Non-disclosure or Secrecy**
  - Positive and negatives of this experience
  - Disclosure expectations
  - How this might affect future disclosures
- **Views on society**
  - Social media
  - Disclosure campaigns
- **Qualities of disclose**
  - Would any qualities make it more or less likely for you to disclose to someone?
  - How would you want someone to respond?
- **Telling your story**
  - How would you tell someone about your experiences? - language
  - Are there any strategies you currently use? E.g. testing someone for disclosure
- **Disclosure goals**
  - What are or would be your goals for disclosure
  - What has influenced them?
  - Do you think disclosure is important?
- **Social Support**
  - How do you feel disclosure impacts on social support and vice versa
- **Self-Stigma**
  - Do you feel self-stigma impacts on your decision to disclose or not disclose?